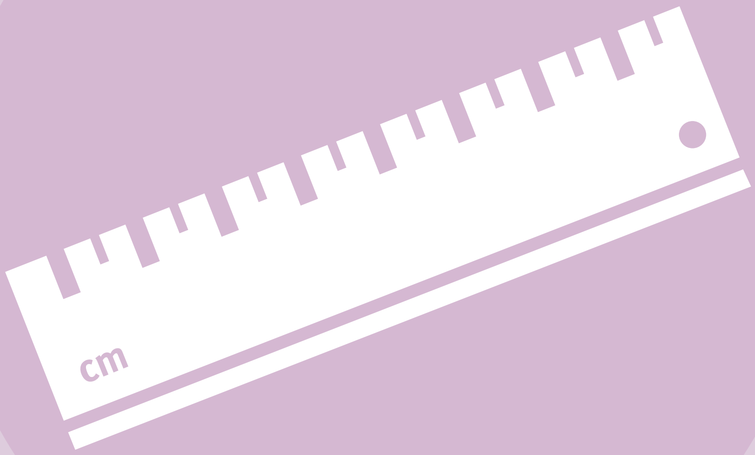
African Palliative Care Association

Standards for Providing Quality Palliative Care Across Africa



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Foreword

The African Palliative Care Association is pleased to publish the first edition of Palliative Care Standards for Africa. The development of these standards was achieved through wide consultation with service beneficiaries and providers, and they have been developed to suit different levels of service delivery, from primary to tertiary.

These standards are underpinned by the World Health Organization's definition of palliative care, and recognise that scaling up palliative care requires a public health approach with four pillars: policy, education, drug availability and implementation. In addition, the increasing need to establish specific indicators of quality and effectiveness for palliative care has been a big driving force behind these comprehensive standards. It is APCA's wish that they will provide a framework for the development of evaluation and performance indicators that can facilitate programme improvement and development.

The standards are designed to allow the development or improvement of palliative care across the different services levels, within the organisational capacity of various service providers. They describe a relationship between primary, intermediary and tertiary level service providers, with expectations for all providers articulated through detailed criteria for each standard. It is therefore expected that these standards will influence the planning and delivery of palliative care services at all levels of health care service delivery.

APCA encourages all health service providers across Africa to adopt these standards and adapt them to their local situations, through the leadership of national palliative care associations and ministries of health.

We acknowledge the efforts of many people and organisations in making this work a reality and would like to recommend these standards as an essential tool and guide for the continued development and provision of palliative care across Africa. APCA remains committed to working closely with service providers at all levels to support the standards' implementation. We anticipate that these standards will help service providers and local accreditation bodies best meet the needs of patients and their families.

APCA will continue to work with palliative care providers across Africa to upgrade these standards as required, as well advocating for their application. Our ultimate goal remains that all Africans with life-limiting illnesses will have access to the best palliative care services wherever these maybe required.

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Acronyms

AIDS	Acquired Immunodeficiency Syndrome
APCA	African Palliative Care Association
ART	Antiretroviral Therapy
ARV	Antiretroviral medicines
CHBC	Community Home-based care
CSF	Cerebrospinal Fluid
EAPC	European Association of Palliative Care
FBO(s)	Faith Based Organization(s)
FEFO	First Expiry First Out
FIFO	First in First Out
FICA	Faith Importance & Influence Community Address/Action
FRI	Family Relationships Index
HAART	Highly Active Antiretroviral Therapy
HBC	Home based care
HIV	Human Immunodefiency Virus
HPCA	Hospice Palliative Care Association
HRM	Human Resource Management
IAHPC	International Association of Hospice and Palliative Care
ICHC	Integrated Community Based Home Care
ICPCN	International Children’s Palliative Care Network
M & E	Monitoring and Evaluation
MER	Monitoring, Evaluation and Reporting
MOU	Memorandum of Understanding
NGO(s)	Non-governmental Organization(s)
NHPCO	National Hospice and Palliative Care Association
OCA	Organizational Capacity Assessment
OI(s)	Opportunistic Infection(s)
ONS	Officer for National Statistics
PC	Palliative Care
PEP	Post-exposure Prophylaxis
PLHIV	People living with Human Immunodeficiency Virus
PLWHA	People Living with HIV and AIDS
POS	Palliative care Outcome Scale
SWS	Safe Water System
TA	Technical Assistance
TB	Tuberculosis
TOR(s)	Terms of Reference(s)
TVP scale	Touch Visual Pain Scale
WHO	World Health Organization
WPCA	Worldwide Palliative Care Alliance

Contents

1.0 An introduction to the standards and the need for standards for Africa

The African Palliative Care Association (APCA), in its mandate of promoting and supporting culturally appropriate palliative care across Africa, is pleased to provide the standards for quality provision of palliative care across the continent. It is important to note that this document has been developed through review of existing palliative care standards across Africa. It is meant to be a quality improvement tool and does not duplicate or replace the clinical standards currently maintained by service providers. It is intended to complement such standards.

1.1 The African Palliative Care Association

Formally established in Arusha, Tanzania, in June 2004, APCA aims to contribute to the African response to the HIV and AIDS epidemic by facilitating the scaling-up of palliative care across the region. It promotes a culturally appropriate public health approach that strives to balance quality with coverage. Its broad objectives are to:

Promote the availability of palliative care for adults and children in need, including Orphans and Vulnerable Children.

Encourage governments across Africa to support affordable and appropriate palliative care incorporated into all health care services.

Promote the availability of palliative care medications for all in need.

- Promote palliative care training programmes specific to the need of African communities.
- Develop and promote quality standards in palliative care training and service provision for different levels of health professionals and care providers.
- Encourage the establishment of national palliative care associations in all African countries.

To achieve the above objectives, APCA's approach is fourfold.

1. To work in collaboration with Ministries of Health and those championing palliative care to ensure that governments and other international donors accept palliative care as a vital component in the care of people with life-threatening conditions so that they include it in healthcare policies and budget lines for funds that will be used to build palliative care capacity across the region.

2. To provide technical assistance (TA) to non-governmental organisations (NGOs) and faith based organisations (FBOs) working on HIV and AIDS and other life-threatening illnesses, to integrate palliative care into their existing programme of work so that palliative care can be recognised as part of the response for the management of HIV and AIDS and other illnesses.

3. To support identified champions of palliative care (both people and organisations) in positions of policy influence so that:

- Palliative care is included in the curricula for all medical and nurse training to increase the skills base so that palliative care provision in the region becomes sustainable;
- Palliative care is incorporated into the health plans of governments, and;
- Appropriate drugs for the relief of pain, symptoms and opportunistic infections are made available.

4. To develop a mentorship programme for new organisations to ensure continued support so this initiative becomes sustainable.

1.2 The need for Palliative Care Standards in Africa

- The fact that palliative care is defined and understood differently in different settings calls for a unified understanding, which can be achieved through the development and implementation of standards.
- To ensure that quality palliative care services are maintained while continuing the current efforts to extend coverage.
- To address current variations in quality of services provided within and between countries.
- To define an absolute minimum quality of services which will enable relative comparisons among countries with comparable levels of resources.
- To inform the expectations of patients and families as service recipients, and staff members as service providers.
- To define the framework and clarify the expectations of communities, service providers, administrators and other stakeholders of palliative care and home-based care across Africa.
- To promote access to comprehensive services.

It is hoped that service providers, administrators and other relevant stakeholders (including palliative care donors) will find these standards a valuable tool for quality improvement and outcome measurement.

1.3 Palliative Care Standards Development:

The need for palliative care in sub-Saharan Africa is significant. By 2008 an estimated 22 million people in the region were living with the Human Immunodeficiency Virus and Acquired Immune Deficiency Syndrome (HIV and AIDS), 67 per cent of the global disease burden, with 1.9 million new infections reported in that year alone.1 Moreover, there were an estimated 7.6 million new cancer cases and six million cancer-related deaths in Africa in 2007,2 while cancer rates on the continent are expected to grow by 400 per cent over the next 50 years.3 Furthermore, there is a growing concern that, as people's lifestyle, nutritional preferences and non-sedentary work patterns on the continent change, Africa may experience an increase in the incidence of chronic, life-limiting diseases.4

The provision of palliative care on the continent is inconsistent, often provided from isolated centres of excellence rather than integrated into the mainstream healthcare system. Indeed, for the overwhelming majority of Africans who currently endure progressive, life-limiting illnesses, access to culturally appropriate, holistic palliative care (that includes effective pain and symptom management) is at best limited, and at worst non-existent.5 A survey of hospice and palliative care services on the continent found not only that 44.7 per cent (21/47) of African countries had no identified hospice or palliative care activity, and that only 8.5 per cent could be classified as having services approaching some measure of integration with mainstream service providers.6 Therefore, as with all healthcare services, people in Africa have a disproportionate need for and lack of access to palliative care services.7 Through a combination of delayed diagnosis, inadequate available resources to treat those diagnosed in time, a lack of skilled palliative care professionals, restricted access to even the most simple pain-relieving medication – not least the strong painkillers (i.e. opioids)8,9– and antibiotics to treat opportunistic infections, as well as anti-retroviral (ARV) therapy, many people living with HIV and AIDS continue to die in pain and without adequate support. In September 2008, the World Health Organisation (WHO) estimated that approximately 80 per cent of the world population has either no or insufficient access to treatment for moderate to severe pain and that every year, tens of millions of people around the world, including four million cancer patients and 0.8 million HIV and AIDS patients at the end of their lives, suffer from such pain without treatment10.

Despite the reported need among care providers, the evidence base that underpins much current palliative care service provision on the continent is inadequate11 and palliative care research remains embryonic.12 Countries and organisations that are trying to integrate palliative care into the services they provide have limited guidance available as to how to do this, and having done it, how to measure the effectiveness of their interventions and programmes.

The necessary steps to achieving high quality palliative care coverage in Africa are enshrined in the Cape Town Declaration, which proposed home-grown solutions for the region13. The components of the declaration, and the birth of APCA, are underpinned both by:

- The recognition of the need to develop culturally appropriate local programmes and models of care by those who understand the challenges posed to service provision in resource-constrained countries, and;
- The importance of identifying local needs and priorities without compromising the quality of palliative care offered.

The need was therefore identified that, as well as increasing coverage of palliative care across the region, it is important to ensure the quality of palliative care provided 14. The primary mode of palliative care service delivery is home-based care (HBC), which is predominantly dependent on volunteers. In addition to addressing the issues of staff recruitment and retention, it is imperative that African palliative care providers ensure that the HBC services provide an acceptable standard of patient care. Moreover, to ensure widespread implementation, it is important that palliative care is integrated into all levels of the healthcare system and delivery models, including the specialist, regional and district (as well as HBC) facilities.

Thus these standards have been developed with the aim of targeting all those in service provision and training for people living with life-threatening illnesses and they are applicable to all settings of care delivery, i.e. home based care, inpatient services, outpatient programmes, day-care programmes, hospital settings and all those innovative models that are currently used in Africa. The standards are also guided by a review of existing home-based care models of people living with HIV and AIDS (PLHIV) to ensure that they are not only relevant to specialist palliative care providers, but to all services including home-based care programmes.

1.4 The process for developing standards

The process of developing standards was highly participatory and was undertaken through consultations with stakeholders at different levels. These included:

- National palliative care associations
- Ministries of Health, National AIDS Commissions and home-based care providers
- Country-based palliative care experts and organisations in HIV and AIDS care and support, and those in cancer care and support
- International palliative care and home-based care experts
- Consultants

These stakeholders contributed to development of various aspects of the standards mainly through committees or consultant work. Core committees which were involved in the development of standards included:

- A Project Advisory committee, made up of international experts and partners
- A standards working group, made up of palliative care and HBC providers and experts from across Africa
- APCA technical team, made up of APCA's technical staff
- An expert review committee, with international experts in palliative care
- Support from WHO and international palliative care organisations such as the International Association for Hospice and Palliative Care, World-wide Palliative Care Alliance

These committees and consultants developed the standards through the following activities:

In November 2004, an APCA standards committee was formed. The committee defined APCA's agenda on standards, from which the current strategy was identified. In 2006, the committee produced the first draft standards.

In 2006, the Elton John AIDS Foundation provided funding for APCA to take the standards to the next level, by ensuring that they are based on, and relevant to, all levels of service delivery, from the very basic to the highly sophisticated. This would provide a 'roadmap' through which service providers might advance from one level of service to another. It is through this project that APCA undertook a review of existing models of care which guided the development of a classification and standards matrix for use across Africa. The process was further broken down into the following steps:

- A review of home-based care models in four countries (i.e. Kenya, Tanzania, Malawi and Zambia), including a literature review and a study
- A review of existing palliative care standards – to inform content and structure of the standards
- Consensus on core areas/ content outline, structure/ format, authors, reviewers, guidelines for drafting, etc.
- Drafting of standards
- Review of draft standards by standards working group
- Review by APCA technical team
- Review by external expert review team
- Final editing and printing

There is a general consensus among supporters and promoters of palliative care globally for countries to integrate palliative care into existing services for PLHIV, including home-based care, but to date there is no review of how this can be implemented. There was also no evidence as to which are the 'best practice' models for home-based care in African countries, or recommendations and guidelines for the integration of all aspects of palliative care into existing home-based care models. Therefore the review sought to address such knowledge gaps on existing models for HBC for PLHIV and provide practical recommendations for the integration of palliative care into existing HBC services.

The results of the review have helped to form a basis on which the standards for palliative care have been developed, in particular with regards to provision of palliative care at community level. It is also anticipated that the results of the review along with the palliative care standards will inform the establishment of an appropriate mentorship support programme for services implementing the palliative care standards.

During the process of the review and following its completion there has been ongoing stakeholder discussion regarding the format of the standards, who they are for and how they should be developed. The principles underlying the standards and their format were agreed on and different experts were assigned different sections to develop in liaison with other relevant stakeholders. The draft document was then reviewed at a meeting in Kampala in March 2009, after which the initial document was finalised ready for dissemination and implementation.

1.5 Principles underpinning the Standards

There are several important principles underlying these standards: the definition of palliative care[15]; the public health approach[16] and integration at all levels of service provision; human rights[10, 21, 23, 25] and core care values[22] and ethical principles[25].

1.5.1 The definition of palliative care

Underpinning the standards is the WHO definition of palliative care for both adults and children:

'An approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of 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 nor postpone death
- Integrates the psychological and spiritual aspects of patient care
- Offers a support system to help patients live as actively as possible until death
- Offers a support system to help the family cope during the patient's illness and in their own bereavement
- Uses a team approach to address the needs of patients and their families, including bereavement counselling if indicated
- Will enhance quality of life, and may also positively influence the course of illness
- Is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.' [15]

The WHO also highlights the need for palliative care for both adults and children, stating that:

'Palliative care for children represents a special field, albeit closely related 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 or not 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'[15].

This is particularly important in the African context where so many children are infected by HIV and AIDS, and will need palliative care at some stage of their life. APCA has adopted the WHO definition of palliative care and additionally included the use of antiretroviral (ARV) therapy, to supplement chemotherapy and radiotherapy, as a 'therapy that is intended to prolong life.'

1.5.2 The public health approach and integration at all levels of service provision

In order to extend coverage of palliative care across the region it is important to understand the public heath approach to palliative care development, which is population and risk-factor oriented rather than symptom or disease oriented. Therefore the implementation of palliative care must be founded on appropriate government policies, adequate drug availability, the education of health professionals, and implementation of palliative care at all levels (see Figure 1)[16].

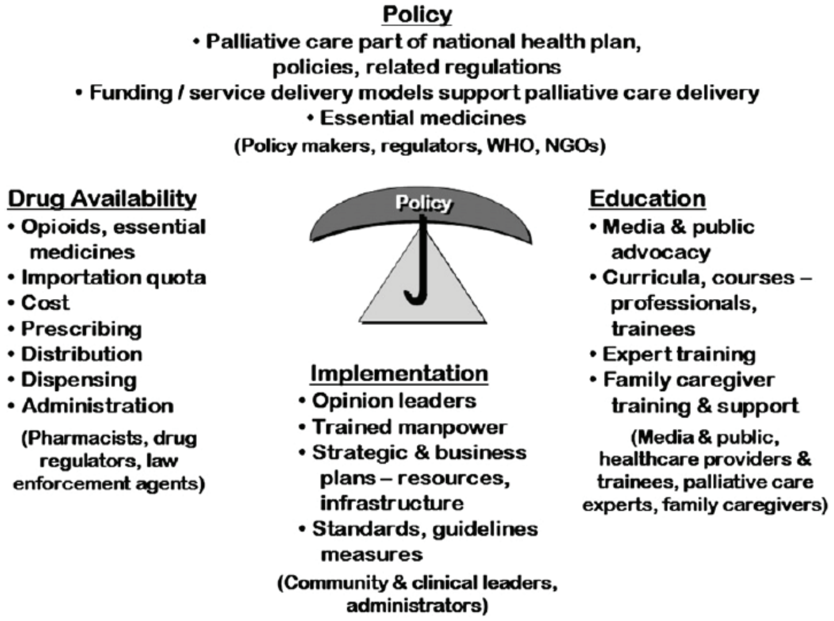

Figure 1: The WHO public health approach

Therefore underlying these standards is the notion that in order to ensure accessibility and availability of palliative care to all, it must be integrated into all levels of national health care systems.[17] Care will be provided at the community level; through local, district and national health facilities, as well as through the provision of specialist palliative care – hence the development of standards across the different levels of service delivery.

1.5.3 Palliative care and human rights

Palliative care is a health service. Yet health is a fundamental human right enshrined in numerous international human rights instruments[10]. Countries have an obligation to progressively implement palliative care services, which, according to WHO, must have “priority status within public health and disease control programmes.”[18] Countries must ensure an adequate policy and regulatory framework, develop a plan for implementation of these services, and take all steps that are reasonable within available resources to execute the plan. As part of this positive obligation, states have to take steps to protect people from unnecessary pain related to a health condition. Failure to attach adequate priority to developing palliative care services within healthcare services will violate the right to health[10]. According to the 2002 Cape Town Palliative Care Declaration, “Palliative Care is a right of every adult and child with a life-limiting disease”.[19] The Korea Declaration on Hospice and Palliative Care of March 2005 agreed that governments must: make access to hospice and palliative care a human right; include palliative care in their national AIDS strategies; include hospice and palliative care in their national cancer control programmes; strive to make hospice and palliative care available to all citizens in the setting of their choice, including acute care hospitals, long-term care facilities (nursing homes), residential hospices and in the patient’s home[20], among others. Excellence in end-of-life care is more than simply good and compassionate medicine; it has an equal foundation in international human rights law[21].

There are various holistic care values that underpin the provision of palliative care. These include the provision of care, with the patient and family being the centre of that care. Holistic care is based on the fundamental principles of human rights and ethical treatment[22]. According to the declaration of Alma-Ata of 1978, primary healthcare requires and promotes maximum community and individual self-reliance and participation in the planning, organisation, operation and control of primary healthcare, making fullest use of local, national and other available resources. To this end, it develops through appropriate education the ability of communities to participate[23]. *Self-determination* and *full participation* of all members of a community in choosing how their resources are distributed to ensure fair, equitable treatment is a core value in good care. An approach which values people with life threatening illnesses as the centre and *owners* of their own care – as people with the lived experience, expertise and solutions to meet their own needs – is most appropriate. To achieve the larger goals of justice and equity, it is imperative that we acknowledge and address PLHIV and other life-threatening illnesses as active agents in the planning and implementation of their own care, support and treatment[23]. No one should have to face their diagnosis, care and treatment, and the possibility of illness and death, alone. While individual members of the community must be at the centre of the care process, they should also be surrounded by family, friends, and the community, who they need and deserve to have, to support them in their care and treatment processes. The community in turn provides support and resources both to the individual being cared for and to one another.

For sustainability of services, it is essential to enable people at different levels of service delivery to act collaboratively in service provision in order to ensure effective use of scarce resources.

Therefore quality care is provided by healthcare workers who:

- endeavour to maintain the ***dignity*** of the patient, their caregiver/s and family
- work with the strengths and limitations of the patient and their caregiver/s and family to ***empower*** them in managing their own situation
- act with ***compassion*** towards the patient and their caregiver/s and family
- consider ***equity*** in the accessibility of services and in the allocation of resources
- demonstrate ***respect*** for the patient, their caregiver/s and family
- ***advocate*** on behalf of the expressed wishes of patients, caregiver/s, families, and communities
- are committed to the pursuit of ***excellence*** in the provision of care and support
- are ***accountable t***o patients, caregiver/s, families and the community[24].

In order to ensure high quality, patient-focused and evidence-based services are available to meet patient needs, primary care and specialist providers, as well as other healthcare professionals, should also:

- follow established practice standards and requirements for quality management such as leadership and governance, human resource management, safe practice, information management and continuous quality improvement
- adhere to professional and organisational codes of practice and ethics
- reflect on and evaluate current practice, and incorporate new evidence into protocols, policies and procedures
- participate in continuing professional development in the knowledge, attitudes and skills required to deliver quality palliative care as this relates to the standards in this document[24].

1.5.4 Basic ethical principles in palliative care

The ethics of care require a delicate balance between the conventional practice of medicine and the wishes of the patient, appreciating that each human situation is unique. Not only should treatment options and likely outcomes be considered, but also patient values, hopes and beliefs. Patients and families must be properly informed to make appropriate treatment decisions and help reset the goals of care at all stages of the illness. Four basic ethical principles25 must be observed in the provision of palliative care services:

The respect for autonomy recognises the right and ability of an individual to decide for him- or herself, based on his or her own values, beliefs and life span. The patient's decision should be informed and well-considered, reflecting his/her values. It is acceptable, for example, that a patient refuse certain therapy according to his own religious beliefs. Many factors interfere with the expression and appreciation of the patient's preferences:

compromised competence of the patient, stress of illness, comprehension difficulty, etc. Respect for autonomy implies truth telling and exchange of accurate information about status, goals of care, options and expectations.

Beneficence requires prevention or removal of harm, while doing or promoting good. It implies that the healthcare team should do positive acts in maximising the benefits of treatment. Examples include: delivering effective and beneficial treatments for pain or other symptoms, providing sensitive support, and assisting patients and families in any way possible.

Non-maleficence supposes that "one ought not to inflict harm deliberately." Violation of this concept may include offering information in an insensitive way, providing inappropriate treatment of pain or other symptoms, continuing aggressive treatment not suitable to the patient's condition, providing unwanted sedation, or withholding or withdrawing treatment.

Justice relates to fairness in the application of care. It implies that patients receive care to which they are entitled medically and legally. Justice can be translated into "give to each equally" or "to each according to need" or "to each his due". The principle of justice implies a consideration for a common good and society.

1.6 Scope of the Standards

These standards for palliative care are applicable to everyone with a life-threatening illness (adults, children and adolescents, the elderly) and their families. The standards do cover the whole continuum of care, including prevention, care and support, and treatment and end-of life care within the context of palliative care. They cover key service components including management, clinical service delivery, and education and training. The standards aim to be flexible and represent the continuum of care provision, and take care of the needs of individuals at all levels of service delivery and across the range of settings in Africa.

The standards target all those in palliative care service provision and training, including national palliative care associations and hospice services. They are applicable to all settings of palliative care delivery, i.e. home based care, inpatient services, outpatient programmes, day care programmes, hospital settings and all those innovative models currently used in Africa.

The standards are based on research, documentation and experience-based evidence, along with international, regional and national frameworks for palliative care service provision for HIV and AIDS and other life-threatening illnesses. The standards have been developed by palliative care stakeholders from across Africa and globally, following wide consultation and participation, and will be reviewed regularly so that they remain relevant and up-to-date. They provide for all stakeholders of palliative care, including service beneficiaries, providers and policy makers.

Special consideration needs to be given to particular groups in the community when applying the standards, particularly those people who are disadvantaged or marginalised[25]. The special needs populations across the region include children with a life-limiting illness, children and young adults with parents who have a life-limiting illness, the elderly, people with mental health problems or substance abuse problems, people who are homeless, refugees and internally displaced people, members of the armed forces, religious leaders, and those who live in institutions such as prisons[26].

1.7 Format of the Standards

The palliative care standards are based on *levels of service delivery* to ensure that, at any level and point of service provision, individuals such as PLHIV and with other life-threatening illnesses are able to access palliative care. The levels are also based on the *setting of care* and *model of service delivery*. They have been derived from a thorough review of: literature on HBC delivery models for PLHIV; the available palliative care standards across the world; the wealth of palliative care experience within and outside Africa; and research on HBC models for delivery of services for PLHIV in Africa. The standards elaborate the quality requirements/ criteria for each level of service delivery. Three levels are used:

- **Level 1: Primary/ Basic level.** This level represents what is essential or the minimum package for palliative care.
- **Level 2: Secondary/ Intermediary.** This represents intermediary services, which provide a wide range of care components.
- **Level 3: Tertiary/ Specialist level.** This represents what is desirable for a specialist palliative care service for people with life-threatening illnesses.

Each of the standards is written in the following format:

a) ***Principle*** – This is derived from the principles and fundamental values of palliative care. Principles are the ideal or fundamental pillars for effective palliative care delivery. An example of this is holistic care provision. There are five principles covered in these standards: organisational management, holistic care provision, children's palliative care, education and training, and research and information management.

b) ***Introduction to the Principle*** – This provides an overview of the principle of palliative care. It presents an outline of all the standards within the principle as well as the general relevance of the principle in palliative care.

c) ***Standard*** – This is the desired achievable level of performance against which actual performance can be measured, i.e. it explains the level of performance to be achieved.

d) ***Intent/ Rationale*** – This provides the reasons why the standard is considered to be important27 and is a further elaboration or interpretation of the standard.

e) ***Criteria –*** This section breaks down the standard into measurable elements. It states exactly what must be achieved for the standard to be reached. Criteria are stated for each one of the service levels elaborated above (i.e. 1, 2 and 3). These criteria also state the methods and tools to be used in measuring the achievement of the standard, along with the role of each level of service delivery and the key players in service provision relating to the standard.

Table 1: Service levels upon which the standards are based

LEVEL(S)	DESCRIPTION	CAPABILITY REQUIREMENTS	RESOURCE REQUIREMENTS
Primary/ Basic level (1)	This level represents what is essential or the minimum package for palliative care. It provides basic clinical and supportive care services and relies heavily on referral of patients and their families to level 2 and level 3 service providers for more advanced and specialist care. General and basic healthcare services, including primary services providing care to PLHIV and their families as well as those with other life-threatening conditions, are required to meet the criteria for level 1 for all standards. Examples - Community based programmes - Primary level government health centres	Uses a holistic approach to manage basic clinical and non-clinical problems of the patient, care givers and families. Provides basic clinical services for Opportunistic Infections (OIs) and uses WHO analgesic ladder level 1 pain assessment and management guidelines. Makes referral to level 2 and 3 service providers for management beyond own capability. Access to ART is by appropriate referral through a documented process. Follow-up on adherence is undertaken in partnership with the service provider for the drugs.	Relies mainly on community care providers and a small team of general healthcare providers. In general, relies heavily on community resources to provide services. Clinical supervision is provided by qualified and experienced professionals.
Secondary level/ Intermediary (2)	This represents intermediary service providers, which are providing a wide range of service components for HIV and AIDS and other life-threatening conditions. Have well developed collaborations with community and other service providers. • All as in level 1, plus: • At least one team member has had a 1-2 week orientation course in palliative care • Ongoing availability of any Step 2 analgesics on site • Availability of ART • OIs management • Receives referrals from, and makes referrals to, level 1 and level 3 service providers, via formal links. • There are limited specialised services Examples - Integrated Community Based Home Care Programmes (ICHC) - Community Home-based care programmes (CHBC) - Government regional and district level services, and other district level service providers such as mission hospitals	Inter-disciplinary team or at least regular access to medical, nursing and psycho-social and spiritual input on site or through a functional and documented referral network. Has formal and informal care providers. Formal care providers give training and support to informal care providers. Access to ART and other medications on site or through referral and a well-documented procedure for follow-up on adherence.	An inter-disciplinary or multi-skilled team with some members of the team trained through specialist palliative care programmes. The actors include professional care providers. A professional team working together with trained community care providers through a well-structured and documented process.

LEVEL(S)	DESCRIPTION	CAPABILITY REQUIREMENTS	RESOURCE REQUIREMENTS
Tertiary Level/ Specialist level (3)	This level provides the full range of palliative care services: comprehensive care for the needs of patients, care providers and families with complex needs. It comprises all elements in levels 1 and 2 plus: • Access to ART on site or through referral • Availability of Step 3 analgesics for use at site and in the home (i.e. oral morphine, methadone) • Availability of palliative radiation and certain palliative chemotherapies at site or a clear procedure of referral for access to such treatments. • Certificate or Degree level training in palliative care represented in the team • All specialist palliative care services are required to meet the criteria for level 3 for all standards. **Examples of services** - Specialist palliative care centres - Hospital-based palliative care units/teams - Palliative Care HBC programmes e.g. ICHC*	Provides specialised palliative care for patients, care providers and families, especially those with complex needs. Physical, social, psychological and spiritual care are all accessed from the same point. Services have the capability to meet the most complex needs and provide a leadership role in palliative care service provision. Receives and manages referrals from level 1 and 2, with clear documentation on the management of such referrals. Can also make referrals back to level 1 and 2 for ongoing joint care. Has formal links with level 1 and level 2 service providers and provides them with consultant support, training and mentorship. Ongoing availability of well structured professional supervision for community care providers. There is a well-documented procedure for follow-up on adherence to medications	A multi-disciplinary team with specialist training, skills and experience in palliative care The actors include doctors, specialist nurses, allied health professionals, spiritual leaders, social care professionals, etc. A professional team working together with trained community care providers through a well-structured and documented process.

* Some service providers such as ICHC can fit in more than one level depending on their capability and resources

1.8 Implementing the standards

f) These standards will be used alongside existing related standards or guidelines, such as treatment guidelines for HIV and AIDS, guidelines for pain management and guidelines for the treatment of opportunistic infections such as tuberculosis, etc. It will be important for service providers and national associations to advocate for the alignment or incorporation of palliative care standards with or into major local accreditation processes, so that they are used in conjunction with or as part of overall service accreditation. In all countries, service providers are encouraged to adapt or adopt the standards to their local situations through the leadership of national palliative care associations and local ministries of health.

g) The implementation of standards will vary with the needs of each service provider. APCA is committed to providing ongoing technical assistance in the implementation of the standards, using local expertise, resources and opportunities where applicable. As much as possible, service providers are encouraged to take responsibility for their own development, and to identify resources for the implementation of the standards.

h) The standards will also be used for the assessment of palliative care provision within the region and will undergo regular review. Service providers are therefore encouraged to provide APCA with feedback on the use of the standards in key areas, such as whether indicators (criteria) are feasible and their appropriateness to the needs of service providers, local accreditation bodies, and patients and their families.

i) The standards are a guide to the improvement of the quality of palliative care services across all levels of service delivery. They offer guidance for managers and the quality improvement professionals within health service facilities to improve their palliative care related health services. The standards offer a model framework[28] that may be used for:

- Developing and/or strengthening national quality evaluation and mentorship programmes for healthcare programmes providing palliative care
- Developing public policy related to palliative care
- Improving the quality of current palliative care programmes
- Creating new palliative care programmes and integrating palliative care into existing healthcare structures
- Building the capacity of communities and facilities to provide more effective and efficient palliative care.

Following the development of these standards, APCA has developed and piloted Standards Audit Tools as well as guidelines for its adaptation. This will facilitate audit, self-assessment and peer to peer assessment to ensure continuous quality improvement.

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PRINCIPLE 1.0: Organisational Management

Introduction to the principle:

Governance is the set of policies, roles, responsibilities and processes that a governing body within an organisation uses to guide, direct and control its resources to accomplish organisational goals. Governance can help protect an organisation from security threats or non-compliance liability[1]. Every organisation has unique needs and goals that will affect its approach to governance. No single approach will fit the cultures or requirements of all organisations. For example, larger organisations will probably require more complex governance processes than smaller ones. This standard is provided with this notion in mind, making provision for the expectations at different levels of organisational operation.

Leadership is defined as 'a process that is ultimately concerned with fostering change, in contrast with management which suggests preservation and maintenance. Leadership also implies intentionality, in the sense that change is not random but rather is directed toward some future end or condition which is desired or valued'[2].Management is about directing and controlling resources according to established principles. This means that governance, leadership and management need to work together for effective organisational operations.

Human resource management (HRM) is the strategic and coherent approach to the management of an organisation's most valued assets – the people working there who individually and collectively contribute to the achievement of the objectives of the organisation[3].

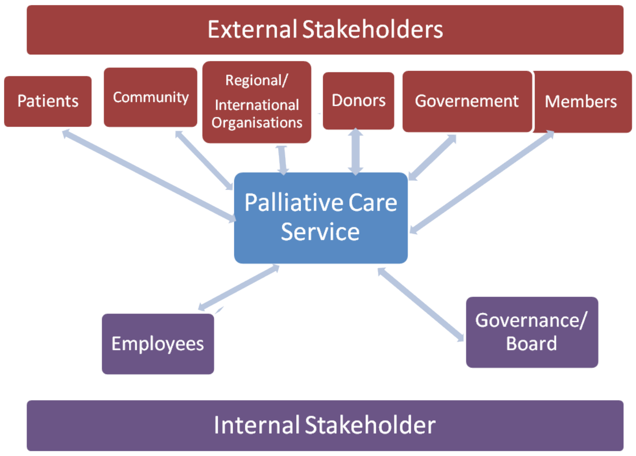
The terms 'human resource management' and 'human resources' (HR) have largely replaced the term 'personnel management' as a description of the processes involved in managing people in organisations[4]. Simply, HRM means employing people, developing their resources, utilising, maintaining and compensating their services in line with their jobs and the organisational aims.

The Human Resources Management (HRM) function includes a variety of activities; key among them is deciding the staffing needs for the organisation; whether to use independent consultants or to have employees to fill these needs; recruiting and training the best employees; ensuring they are high performers; dealing with performance issues, and ensuring that personnel and management practices conform to the legal and statutory or labour laws in the country of operation. Activities also include managing the approach to employee benefits and compensation, employee records, and personnel policies (which are often in the form of employee manuals, which all employees must have). The HRM approach seeks to ensure a fit between the management of an organisation's employees, and the overall strategic direction of the organisation.

Performance management includes activities to ensure that goals are consistently being met in an effective and efficient manner. Performance management can focus on performance of the organisation or a department, and processes to develop a service or employees' output[5]. Performance management reminds staff that being busy is not the same as producing results, and that training, strong commitment and hard work alone do not equal results. The major contribution of performance management is its focus on achieving results. Performance management redirects efforts away from busyness toward effectiveness.[5] Consequently performance management should focus on the organisation, whether it is meeting its goals or not, its departments, its processes and whether polices are being carried out in line with available resources and systems. This includes budgeting for personnel and financial management and programmes, looking at the implementation of new policies and new areas of work, services to internal or external clients, and team work (which looks at how groups are organised to accomplish a result or an activity).

Palliative care promotes a safe caring environment. A key component of a safe working environment is infection control. In particular, the risk of occupational exposure to TB, HIV and other infectious diseases in healthcare settings is a serious reality. It is the duty of administrators and every health worker to identify and decrease the risks of infection for patients and families as well as palliative care providers. By observing universal precautions in infection control, the health worker can protect him/herself as well as the patient and the family by reducing the risk of disease transmission.

A stakeholder is anyone who is a party who affects, or can be affected by, the organisation's actions. The stakeholder concept was first used in a 1963 internal memorandum at the Stanford Research Institute. It defined stakeholders as 'those groups without whose support the organisation would cease to exist.'[6] For every organisation stakeholders can be divided into internal and external stakeholders, as shown in the figure below.



The relationship with these entire stakeholders is important for the wellbeing of the organisation and also in ensuring that the organisation reaches its goals and objectives. Within palliative care the stakeholders are normally the international, regional and national palliative care associations, palliative care beneficiaries (patients and their families), individual organisations providing care, and other interested parties such as donors. This standard provides the expectations with regard to the relationships with all these stakeholders

Standard 1.1: Governance, Leadership and Management

A formal governance, leadership and management structure is in place that permits and supports the decision making process and implementation of all issues within the organisation. Central to this structure is the vision and mission of the organisation. This structure is supplemented by an appropriate philosophy, values, culture and an environment for the provision of competent and compassionate palliative care, and a safe working environment for service providers.[1]

Intent/Rationale

The purpose of this standard is to ensure that an organisation is governed and led with clear governance, leadership and management/operational polices that guide its operations in line with the legal and statutory requirements in the country of operation. Adhering to this standard will ensure that the organisation has credibility and accountability.

It is anticipated that once the policies are in place, this will provide clear direction to the organisation as it will clarify the purpose and mission of the organisation and make provisions for how decision making will be managed and implemented. A clear purpose of the organisation will help to plan how to obtain and allocate resources, including making decisions on whether to raise money from donors or to earn it by making and selling items or services from the organisation. In addition the policies will provide clarity on who holds the ultimate authority and responsibility for the organisation, and clear avenues for conflict resolution.

Ultimately the polices should also provide a clear philosophy, values and culture that will guide the work of the team in achieving quality palliative care services for patients and their families, in line with the organisation's vision and mission.

Criteria

Primary/Basic level (1)

There is compliance with legal and statutory requirements within the country or local setting of operation; these may include developing memoranda of articles of operation/constitution, and organisation registration with the relevant authorities.

i. An organisational governing body is in place with clear and documented nomination procedures, i.e. in the constitution, and in a separate nomination policy.

ii. The governing body is selected from people representing a variety of skills as well as representatives from the population that the organisation serves. It meets regularly and minutes are recorded and signed.

iii. There is clear leadership at the operational level.

iv. There is documented role differentiation at the governance and the operations levels (day-to-day management).

v. The leaders ensure that all people providing care or administrative services within the organisation are competent and adhere to the laid-out clinical procedures and regulations for the organisation.

vi. The leaders and managers provide a clear system of minimum data collection across all areas of the organisation.

vii. There is clear role differentiation for all staff at the operations level, e.g. there are job descriptions or work schedules, employee contracts, training policies, regular supervision and support, discipline and dismissal procedures. Volunteer contracts are all documented and in use.

viii. Organisational leaders ensure that both staff and volunteers are provided with a safe workplace and that they are valued, respected and supported in their work.

ix. The budget is approved annually by the governing body and the approval documented.

x. There is ongoing monitoring and review of the budget by the organisation's leadership.

xi. A cash book and bank reconciliations are maintained for all financial transactions.

xii. There is a record of annual activities.

Secondary/Intermediary level (2)
All of level 1 plus:

i. There are documented policies and procedures that govern the overall operations of the organisation, including staff manuals and management and financial guidelines, and these undergo annual review.

ii. There is a documented work agenda or goals or strategic plan that the organisation is working towards, including the vision, mission and objectives plus documented progress reports. This is reviewed regularly.

iii. A documented policy on volunteers is in place addressing the role of the volunteers, reimbursements and records of volunteer activities.

iv. Documented mechanisms are in place with regard to referrals or networks and follow-up mechanisms.

v. The organisation's leaders and managers have a clear system for ongoing monitoring and evaluation of the adequacy of the organisational resources by reviewing the annual budgets.

vi. Members of the governing body have developed and implemented a written conflict of interest policy that includes guidelines on conflict of interest resolution.

vii. There are clear roles and responsibilities for the governing body and all members undergo an induction programme.

viii. There is a written procedure for annual assessment of the governing body, which is implemented annually.

ix. The terms of office and transition system for the members of the governing body are well documented.

x. There is evidence that the governing body provides leadership, guidance and policy direction for the organisation, to ensure that it remains focused on its vision, mission and strategic plan. These are reviewed regularly.

xi. There is documented evidence to demonstrate fiscal responsibility (the legal duty to act in the best interests of beneficiaries) and fiduciary (financial) responsibility for the organisation, e.g., funding contracts or agreements with donors; registration; insurance; permits; lease agreements; licences, copyright; protection against defamation; occupational health and safety; taxation; pay-roll (all examples also apply to criteria(i) in level 1).

xii. Annual finance statements and audit reports are reviewed by the governing body.

xiii. Important organisational activities are documented in an Annual Report.

xiv. The leaders ensure there are mechanisms in place to manage finances and that appropriate donor reports are submitted in a timely manner based on donor requirements.

xv. The organisational leader (i.e. Chief Executive Officer) is selected by the governing body to implement the policies it sets.

xvi. Annual financial audit is conducted by an external but recognised financial auditor in accordance with the organisation's financial year.

Tertiary Level/Specialist level (3)
All of level 2 plus:

i. The organisational leaders provide written administrative and clinical procedures which direct day-to-day operations of care provision. These are reviewed regularly.

ii. The organisational leaders and managers ensure that there is a process to review the quality of care provided.

iii. There is a documented quality improvement programme which is implemented.

iv. The governing body puts a process in place to support the development of future organisational leaders.

v. The governing body has a documented succession policy that all staff and volunteers are aware of.

Standard 1.2: Human Resource Management

Formal policies and procedures are in place that direct the organisation's human resource management.

Intent/Rationale

The purpose of this standard is to guide organisations in organising and managing their human resources. The standard recognises that organisational staff, if properly managed, can greatly increase the output of any given organisation. This can also address issues of staff retention.

Criteria

Primary/Basic level (1)

i. Human Resources policies and supporting procedures are in place and in line with current labour legislation of the country.

ii. All records of interviews and references are retained for a minimum of five years, including internal and external advertisements.

iii. There are employment agreements and job descriptions for staff and volunteers.

iv. Staff and volunteers are provided with opportunities for ongoing training.

v. There is evidence of an application pack containing a form where potential staff declare whether or not they have been or are currently the subject of any police investigation or conviction in this or any other country.

vi. There is an individual personnel filing system in place for all employees.

vii. Human resource policies and procedures make provision for volunteers.

Secondary/Intermediary level (2)

All of level 1 plus:

i. Policies define how recruitment criteria for selection, interviews, induction, employment and retention of staff are managed.

ii. Contracts, job descriptions, performance reviews and appraisal systems are in place. Performance appraisals reflect key objectives.

iii. There is a documented recruitment and retention strategy for volunteers.

iv. A programme for ongoing training and continuing education for staff and volunteer development is in place.

i. A training record of all education and skills development opportunities and activities is kept for each member of staff.

ii. There is a dedicated person responsible for the human resource portfolio.

iii. There is documented annual return that shows the diversity of staff and volunteers, which correlates with the community the organisation serves.

iv. Annual appraisals are conducted and forms completed and filed in individual personnel files.

v. Annual work plans are agreed with all staff and documented to support the review above.

Tertiary Level/Specialist level (3)

All of level 2 plus:

vi. The human resource function is placed within a larger organisational development department to support all functions of the organisation.

vii. Human resource training courses and guidelines are developed and implemented.

viii. Mentorship and training is made available to level 1 and level 2 organisations.

Standard 1.3: Performance Management

Formal policies and procedures are in place that direct the organisational performance management and are linked to the organisational vision, mission and goals.

Intent/Rationale

The purpose of this standard is to ensure that organisations have in place well-documented procedures for measuring performance at all levels of the organisation. This helps the organisation to know that it has achieved its goals; the staff are productive and resources are used in line with the organisation's objectives and aims.

Criteria

Primary/Basic level (1)

i. The vision and mission of the organisation are documented and known by staff and volunteers.

ii. Individual performance contributes towards achieving the mission and vision of the organisation.

Secondary/Intermediary level (2)
All of level 1 plus:

i. Documented policies and procedures to guide performance management are in place.

ii. Policies and procedures are reviewed and updated at least every two years.

iii. Expected performance levels of staff are linked to job descriptions, which are linked to the organisation's vision and objectives.

iv. The governing body undertakes the organisational performance appraisal every three years or at the end of each strategic plan.

v. Staff and volunteers are orientated and understand performance management policies and procedures.

vi. Line managers undertake and document annual performance reviews.

vii. The organisation has a clear strategic plan, in line with its vision, mission and goals.

viii. Organisational performance indicators are agreed on by the governing body and linked to the strategic plan.

ix. The organisation has clear policies and procedures on performance management, which are reviewed and updated at least every two years.

x. Performance management is carried out at all levels of the organisation, including governance level, using tools such as the organisational capacity assessment tool (OCA).

xi. Expected performance for each position in the organisation is covered in the orientation and induction programme.

xii. Each employee's job description is reviewed and key performance areas and indicators updated prior to/during the performance appraisal meeting.

xiii. Employees document their individual strengths and challenges relating to achieving the key performance areas and indicators of the position.

xiv. Line managers document employees' strengths and challenges relating to key performance areas and indicators and discussed them with employees at the formal appraisal session.

xv. Tertiary Level/Specialist level (3)

xvi. All of level 2 plus:

xvii. Performance standards are specific, measurable, achievable, relevant and time-bound.

xviii. Performance standards are set in line with the operational requirements of the organisation.

xix. Line managers and employees agree on personal development needs for employees and these are regularly reviewed and documented.

xx. The organisation consolidates all individual personal development needs into one personal development plan for the organisation.

xxi. Adequate budget provision is made for personal development for all staff and volunteers.

xxii. There is a documented system in place for peer appraisal.

xxiii. Guidelines regarding performance appraisal are developed and implemented.

xxiv. Training and mentorship regarding performance management is provided to level 2 organisations.

Standard 1.4: Risk management

Formal policies and procedures are in place that direct the organisational risk management process, in line with the organisation's vision, mission and goals.

Intent/Rationale

The purpose of this standard is to guide organisations in issues around risk management. It aims to ensure that the care provider is well trained and able to articulate the importance of his or her own safety, as well as that of patients and their families, and adhere to universal precautions *(summarised in appendix 1)* in the course of delivering and receiving care.

Criteria

Primary/Basic level (1)

i. Organisations are registered with the local health body in the country, such as the Ministry of Health.

ii. Government health policies, especially those encompassing universal precautions in infection control, are known by staff, are accessible and are implemented.

iii. Staff and volunteers are appropriately qualified for the level of service offered and demonstrate ongoing participation in continuing professional development[7].

iv. Staff have access to basic safety requirements, such as soap and water for hand washing; gloves, aprons and masks (protective wear), and the proper disposal of waste.

v. Organisations put measures in place to ensure the safe disposal of hazardous medical waste.

vi. There is access to post-exposure prophylaxis (PEP) in case of significant exposure to the HIV virus in both professional care providers and family care providers.

vii. Care providers, patients and their families are educated about TB control and prevention measures, and make appropriate referrals to level 2 and 3 when required.

viii. Care is taken to ensure the safety of staff from violence from patients or their families or physical harm during the course of their work.

Secondary/Intermediary level (2)
All of level 1 plus:

i. There are containers for sharp objects such as needles (not recapping needles).

ii. Health education is provided to patients and their families regarding the safe use and storage of morphine and other medications.

iii. The service develops and implements a documented infection control programme for professional care providers as well as patients and their families.

iv. Policies and procedures for TB control are developed, reviewed periodically, and evaluated for effectiveness to determine the actions necessary to minimise the risk for transmission of TB[8].

v. Staff and volunteers reflect on practice and initiate and maintain effective self-care strategies to reduce the risk of burnout through formal and informal mechanisms that provide support for individuals[7].

vi. There is a comprehensive risk management programme in place which addresses the management of real and potential physical, environmental, financial, operational and medico-legal risks.

Tertiary Level/Specialist level (3)
All of level 2 plus:

i. There is policy in place to ensure that, within a multi-disciplinary and inter-disciplinary team, an identified team member is responsible and accountable for the management and treatment of the patient and their family[9] at a certain point in time.

ii. Training and mentorship in risk management is made available to level 1 and 2 organisations.

Standard 1.5: Roles of Stakeholders

A formal guideline on stakeholder relationships is in place that will enable organisations to relate with their stakeholders to enhance sustainability, collaboration, information sharing and networking.

Intent/Rationale

The purpose of this standard is to guide organisations in the development of relevant and appropriate stakeholders, undertaking stakeholder assessments and utilising different levels of stakeholder for the betterment of the organisation and its beneficiaries. It is assumed that all organisations will have some level of stakeholder involvement both at formal and informal levels, and this standard will provide guidelines for both. It will also provide guidelines for internal stakeholders.

Criteria

Primary/Basic level (1)

i. There is a process of consulting and providing feedback to internal stakeholders.

ii. Regular staff meetings take place, which are documented and the minutes circulated.

iii. There are regular leadership meetings to discuss day-to-day running of the organisation and how organisational goals are being addressed.

iv. Service providers have a record of their external stakeholders and network organisations, their work and the nature of the relationship engaged in.

v. There is a mechanism known to staff for liaising with external stakeholders.

vi. Documented systems are in place to show how the stakeholders receive ongoing updates on the work of the organisation. This could include annual stakeholder meetings or informal gatherings.

Secondary/Intermediary level (2)

All of level 1 plus:

i. The process for identifying and networking with external stakeholders is documented.

ii. Roles and responsibilities of different external stakeholders are documented.

iii. There is a process for receiving feedback from stakeholders and a mechanism for dealing with their feedback.

iv. There is a documented system in place to identify who the organisation’s external stakeholders are. This could include a stakeholder assessment register or a simple mapping exercise.

v. Stakeholder records are well-maintained and not shared without consent.

vi. Paying members’ benefits are well-documented and shared with members. A clear fee structure is documented and approved by the governing body.

vii. The system of fee collection is clearly documented and implemented.

viii. Where an organisation is representing other organisations, e.g. national entities and associations, there is a documented communication strategy with its members, and role differentiation between the national entities and the individual members or organisations.

ix. Where there is overlap between the activities of a national entity or association and its members, a clear memorandum of understanding (MOU) or terms of reference (TOR) is developed to provide clarity.

x. The different levels of stakeholder are identified and documented in the constitution that governs the organisation.

xi. A stakeholder analysis is regularly undertaken to determine how the service provider relates with the different stakeholders, and this is documented.

xii. Stakeholders’ needs assessment is completed annually to identify whether these needs are the same or changing.

xiii. The governing body encourages feedback from staff and management (internal stakeholders). This could be given through occasional meetings with groups of staff and managers.

xiv. Stakeholder liaison responsibility is designated to an identified person or portfolio within the organisation.

xv. There is an effective referral network in place which contributes to the provision of a continuum of care for patients and their families.

xvi. Mentorship and training regarding effective networking is made available for level 1 organisations.

Tertiary Level/Specialist level (3)

i. All of level 2 plus:

ii. The governing body ensures that stakeholder consultative forums are held periodically to obtain the views of stakeholders on matters of interest.

iii. The governing body and the organisational leadership respond quickly and proactively to stakeholder concerns.

iv. Polices are in place that ensure cultural sensitivity and appropriate responses to culture-specific perceptions of problems and risks.

v. The organisation invests in different and documented ways of conflict resolution with stakeholders.

vi. Effective networks are established to promote palliative care nationally and internationally.

vii. Updates about international networking opportunities are available for level 1 and 2 organisations.

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3. Armstrong, Michael (2006). *A Handbook of Human Resource Management Practice* (10th ed.). London: Kogan Page. ISBN 0-7494-4631-5. OCLC 62282248
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5. Performance Management, What do we mean by performance? A complete integrated online library for non-profits and for-profits; www.managementhelp.org/perf_mng/defntion.htm, (accessed May 2009).
6. *Stockholders and Stakeholders: A new perspective on Corporate Governance.* By: Freeman, R. Edward; Reed, David L., California Management Review, Spring83, Vol. 25 Issue 3, p88-106
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9. Doyle, D; Hanks, GWC; MacDonald, N: *Oxford Textbook of Palliative Medicine*, Second Edition; page 23

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1. National Hospice and Palliative Care Organisation’s (NHPCO’s) *Hospice Standards of Practice for Hospice Programs* (2006)
2. Council for Health Service Accreditation of Southern Africa (2004) Hospice Palliative Care Standards. CHOSASA, South Africa.
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PRINCIPLE 2: Holistic Care Provision

Introduction to the principle:

By definition, palliative care encompasses a holistic approach to care, i.e. it is care that addresses the whole person: physical, psychological, social, spiritual and cultural[1]. Thus care is provided, where possible, by a skilled multi-disciplinary team who can give the most appropriate care that supports and responds to the needs of patients and families. The plan of care is based on a holistic assessment that takes into account the individual's physical, psychological, social, spiritual and cultural needs[2]. Such an assessment is undertaken using a holistic tool (see example in appendix 2), and the outcome of care is measured using simple, rigorously validated multidimensional outcome instruments, such as the APCA African Palliative Care Outcome Scale[3] (Appendix 3). Following the identification of needs, a plan of care is devised, in conjunction with the patient and their family (including children), which is then implemented and evaluated on a regular basis. Good communication skills are key to the delivery of palliative care, enabling assessment along with discussions with the patient and their family about treatment options, prognosis and breaking bad news[4]. In the holistic approach to care, it is important to take into account complementary therapies and relevant legal and ethical issues. Care needs to be coordinated between different service providers, ensuring that patients have access to care through a system of collaboration, networking and referral[5].

Standard 2.1: Planning and Coordination of Care

The plan of care is based on needs identified through a holistic assessment, and is implemented and evaluated in partnership with the patient and their family. A designated individual is responsible for the coordination of care.

Intent/Rationale

Assessment is a prerequisite to effective care planning. An assessment of the patient and family must take into account physical, psychological, social, spiritual and cultural needs. On identification of patient and family needs, a plan of care can be drawn up by the inter-disciplinary team, where available, in conjunction with the patient and the family. The needs of the patient are continually assessed throughout the implementation of the plan of care, which is amended and updated as needs change. The planning and delivery of care should ensure the involvement of care providers with different skills, in line with the service provider's policies and procedures. The coordination of care is dependent on the exchange of information and referrals between members of the team within and between the levels of care[6 7 8].

Ensuring quality of care requires that clear goals of care are established and that a patient receives the available services in a coordinated manner[9].

Criteria

Primary/Basic level (1)

i. A basic assessment is carried out for each patient and their family, and physical, psychological, social and spiritual needs identified.

ii. A basic plan of care is developed, based on the needs identified.

iii. Care plans are reviewed under the supervision of a professional care provider and appropriate referrals are made to other care providers according to need.

iv. One person from the service provider is designated as the patient's key care provider. The patient and family know who that person is.

v. Patients and families receive adequate information to enable them to participate in care decisions.

vi. Referral networks are in place to level 2 and 3 service providers in order to meet the unmet needs identified.

Secondary/Intermediary level (2)

i. All of level 1 plus:

ii. A named professional care provider is responsible for a comprehensive assessment of the patient and their family, and the planning of their care.

iii. The documented care plan is regularly reviewed by the professional care provider.

iv. The person responsible for individual patient care has received training in palliative care.

v. The identified needs of the patient and their family are addressed by an inter-disciplinary or multi-skilled team.

vi. Referral networks are in place from and to level 1 and 3 service providers, to meet the unmet needs identified.

vii. There is documented evidence that care is provided in an effective and appropriate manner, with the goal of achieving a level of comfort acceptable to the patient and family.

Tertiary Level/Specialist level (3)

All in level 2 plus:

i. A comprehensive assessment of unmet and complex needs is undertaken and a plan of care developed and implemented.

ii. The inter-disciplinary team meets on a regular basis in order to discuss existing challenging patients, referrals, new patients, and death and bereavement issues.

iii. Referral networks are in place from and to level 1 and 2 service providers in order to meet the needs of the patient and their family.

iv. Medical, nursing, psychological and other clinical leaders plan and implement an effective organisational structure to support their responsibilities and authority.

v. Patient records reflect that the patient and their family receive care consistent with the policies and procedures of the organisation and professional standards.

References:

1. Mpanga Sebuyira L (2006) Chapter 2: Overview of HIV and AIDS and Palliative Care. In Gwyther L, Merriman A, Mpanga Sebuyira L and Schietinger H. A Clinical Guide to Supportive and Palliative Care for HIV and AIDS in Sub-Saharan Africa. APCA, Uganda.
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6. Hospice Casa Sperantei (2002) National Standards in Palliative Care, Romania.
7. Council for Health Service Accreditation of Southern Africa (2004) Hospice Palliative Care Standards. CHOSASA, South Africa.
8. Clinical Standards Board for Scotland (2002) Clinical Standards Specialist Palliative Care. CSBS Edinburgh
9. Holland J.C, Chertkov L. (2004). Clinical Practice Guidelines for the Management of Psychosocial and Physical Symptoms of Cancer. http://books.nap.edu/html/palliative_care/ch7.pdf

Standard 2.2: Access to Care

Patients in need of palliative care have access to services through collaboration, networking and referral.

Intent/Rationale

Palliative care should be available at all levels of care and is enhanced by collaboration and networking so that patients with life-threatening illnesses can access services throughout the continuum of care1. The components of care provided at each level will vary, so there is need for referrals and networking in order to offer the full range of palliative care services, along with other services that may be required[2 3 4]. This standard is focused on ensuring access to palliative care. Ready access to community resources is important[5].

Criteria

Primary/Basic level (1)

i. Sensitisation of local stakeholders about palliative care and its availability in the community is conducted by service providers.

ii. Service providers provide basic palliative care services.

iii. Service providers have a list and contacts of community resources[5] and other important stakeholders where patients and their families can be referred to access specific services.

iv. Service providers work in collaboration with other organisations.

v. Local networks and referral systems are in place.

vi. Referral networks are in place to level 2 and 3 service providers to ensure that there is clinical support for the patient and their family when needed.

Secondary/Intermediary level (2)

All of level 1 plus:

vii. Service providers are able to provide comprehensive palliative care services.

viii. Care is supervised by a professional care provider who has had palliative care training.

ix. Referral networks are in place to level 1 and 3 service providers to ensure that there is clinical support for the patient and their family when needed.

Tertiary Level/Specialist level (3)

i. All of level 2 plus:

ii. Care is supervised by a specialist palliative care provider.

iii. Referrals are accepted from level 1 and 2 service providers to ensure that there is clinical support for the patient and their family.

iv. Service providers have documented policies and procedures with regards to collaboration, networking and referral systems.

v. Mentorship is provided to level 1 and level 2 service providers with regard to establishing and maintaining an effective referral network.

vi. The impact of care on patients and their families is measured and documented.

vii. Quality improvement activities are undertaken to improve patient and family outcomes.

References:

1. Defilippi K and DiSorbo P. (2006) Chapter 37: Partnerships and Collaboration. In Gwyther L, Merriman A, Mpanga Sebuyira L and Schietinger H. A Clinical Guide to Supportive and Palliative Care for HIV and AIDS in Sub-Saharan Africa. APCA, Uganda
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5. Holland J.C, Chertkov L. (2004). Clinical *Practice Guidelines for the Management of Psychosocial and Physical Symptoms of Cancer*. http://books.nap.edu/html/palliative_care/ch7.pdf

Standard 2.3: Communication in palliative care

Effective communication takes place between the patient, their family and the care provider.

Intent/Rationale

Effective communication, which meets the needs of the patient and their family, is essential in palliative care. The majority of palliative care patients express a preference for the care provider to give as much information as possible, be that good or bad news1. Although communicating the truth can be painful, not communicating accurate essential information to patients may well provoke greater problems.1 Attempts to protect patients from the reality of their situation often create further problems and can lead to inconsistent messages being given by other members of the inter-disciplinary team. Good communication facilitates appropriate referrals, inter-disciplinary assessment, continuity of care, discharge planning, end-of-life care and bereavement support, as well as conflict resolution and stress management. Poor communication is a threat to patient care and a source of staff stress2. A team of reliable professionals who are communicating well with each other provides patients with a sense of security, consistency and comfort2.

Communication and sharing information with regard to prognosis and goals of care is essential for quality care[3]. Identification and management of symptoms, physical and psychological, hinge on interaction[4]. The act of communication is an important part of therapy and occasionally, it is the only intervention[5]. Family members often recall in detail the sensitivity (or lack of it) of the doctor and staff as their relative was dying. These memories affect the grieving process: how the family was told about what was being done, how they were informed of the changes in the medical situation, and especially how attentive the doctor and staff were in controlling the patient's distress and physical symptoms[6].

Criteria

Primary/Basic level (1)

i. Care providers are trained in how to communicate with patients and families in an empathetic, compassionate and supportive manner[4].

ii. Basic information needs of the patient and the family especially in important areas such as disclosure, diagnosis, prognosis and transition to palliative care are identified and addressed on site or through referral.

iii. Family members and care providers are educated on how to manage pain, distress and other symptoms in the patient and how to communicate with the patient and professional care providers[4].

iv. There are mechanisms for communicating with patients and families who do not speak commonly used languages.

v. Care providers find out what the patient understands; they learn how much more or less information the patient wants to know; are sensitive to and empathetic with whatever emotions the patient expresses; listen attentively and allow tears and emotions to be expressed without rushing the patient, and take into account the family and its ethnic, cultural and religious roots[4].

vi. Communication is designed and delivered to improve relationships at all levels, including family, care providers and the community.

vii. Communication identifies the patient's fears and concerns and advises on the resources available as well as all holistic needs, including psychosocial concerns.

Secondary/Intermediary level (2)
All of level 1 plus:

i. The process of identifying and meeting the information needs of patients, families, volunteers, local policy makers/politicians and professionals is documented.

ii. Information needs of the patient and family are identified, and written information that is locally relevant is provided to patients, their families, care providers, policy makers and the media.

iii. Care providers are given formal training in basic interviewing, assessment and counselling skills, and further communication skills training to improve attitudes, confidence and skills.

iv. Accurate documentation of ongoing communication from the multidisciplinary team is completed and feedback given.

v. Family meetings are used for identifying and meeting patient and family information and care needs, as well as understanding family dynamics (*see a guide in appendix 4)*.

vi. Referral is made so that complex communication needs can be met, and is documented – including follow-up for feedback.

vii. There is a system for discussing disease progression and end-of-life care[4].

viii. Care providers initiate research on communication skills in palliative care provision.

ix. Issues around palliative care are communicated to the public, politicians and the media in order to influence policy decisions, resource allocation and service utilisation.

Tertiary Level/Specialist level (3)
All of level 2 plus:

i. Care providers have received advanced training in communication and, where appropriate, counselling skills, through the use of practical and reflective teaching methodologies such as videotapes, role playing, etc.

ii. Complex communication needs are identified and met.

iii. There is a family therapist, social worker or communication specialist to support the team with complex communication needs, or access to such services through collaboration and networking.

iv. Service providers are undertaking research relating to communication in palliative care.

v. Guidelines for communicating with patients and their families are developed and implemented, especially those relating to talking to patients about death and associated fears and uncertainities[4].

vi. Mentorship and training regarding communication is made available for level 1 and level 2 service providers.

References:

1. Fallowfield L. Communication with the patient and family in palliative medicine. In: Doyle, Hanks et al (2005), *Oxford Textbook of Palliative Medicine*. Oxford University Press. PP.102
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Standard 2.4: Pain and Symptom Management

A patient's pain and other symptoms in all domains – physical, psychological, social and spiritual – are identified and managed in partnership with the patient and their family.

Intent/Rationale

Effective pain and symptom control is the foundation of palliative care and is best achieved through a team approach to address the problems of psychological, social, spiritual and physical needs of a patient and their family. The important principles of pain and symptom control are medical expertise; quality nursing care; a thorough assessment with full attention to details; regular review and good communication skills with a listening ability[1].

Chronic moderate and severe pain is a common symptom of cancer and HIV and AIDS. Even though the increasing availability of antiretroviral drugs in middle- and low-income countries is prolonging the lives of many people with HIV, pain symptoms continue to be a problem for a significant proportion of these patients[2]. Several studies have found that between 29 and 74 per cent of people who receive antiretroviral treatment experience pain symptoms[3].

Patients do not need to suffer distressing symptoms, including uncontrolled pain. It is possible to significantly control the symptoms of pain, as well as other symptoms with which a patient might present.

An impeccable assessment of symptoms, including pain, is important so as to identify the cause of the symptom and manage it.

Criteria

Primary/Basic level (1)

i. Care providers measure and document pain and other symptoms, and assess and manage symptoms and side-effects[4].

ii. Care providers believe the patient's complaint of pain and undertake a basic assessment of pain and symptoms.

iii. The assessment is documented, dated and signed.

iv. Care providers have routine access to step 1 analgesics, such as Paracetamol/Panadol, Ibuprofen, etc., and can access step 2 and 3 analgesics (*see the WHO Analgesic ladder on* www.who.int/cancer/palliative/painladder/en/) under the guidance of level 2 and 3 service providers.

v. The effectiveness of interventions to relieve pain is documented.

vi. Pain is re-assessed at regular intervals.

vii. Care providers have clear instructions about how to seek help from level 2 and level 3 service providers if needed – in particular out of normal working hours.

viii. There is evidence of appropriate referrals to level 2 and 3 service providers.

ix. There is a clear and easy-to-use referral system to level 2 and 3 facilities, to enable clinical support for the patient and family where possible.

x. Non-pharmacological as well as pharmacological methods of pain and symptom management are provided to the patient.

xi. Care providers communicate to the patient and family about the interventions they are undertaking, to enable the patient to be part of the decision-making process.

xii. A simple medicines chart *(see example in appendix 2)* is developed for use at home by the patient and the family, who are given explanation on how to use the charts.

Secondary/Intermediary level (2)

All of level 1 plus:

i. Care providers are trained in palliative care and the importance of the need to identify patients' symptoms, including pain.

ii. There is a user-friendly assessment tool (*example in appendix 2)* in place that providers use in the assessment of patients' symptoms, which includes pain assessment tools such as a body chart or a visual analogue scale.

iii. Care providers undertake a comprehensive assessment of the patient's pain and symptoms.

iv. Pain and symptom management is included in the care plan.

v. Service providers have routine access to step 1 and step 2 analgesics and can access step 3 analgesics under the guidance of level 3 service providers.

vi. There are adjuvant analgesics available to help in the management of complex pain syndromes, e.g. antidepressants for nerve pain, corticosteroids, etc.

vii. Care providers identify complex symptoms, including pain, and make referrals to level 3 services for advanced management.

viii. Care providers have clear written instructions about how to seek help from level 3 service providers if needed – in particular out of normal working hours.

ix. There is evidence of appropriate consultation with level 3 service providers.

x. There is an inter-disciplinary team available to support the holistic assessment and management of the patient's pain and symptoms, and/or a network system for provision of such a service.

xi. Side-effects of medications are anticipated and actively treated as appropriate.

xii. There are referral networks in place to a level 3 service provider to ensure that there is clinical support for the patient as needed.

xiii. There is regular inter-disciplinary, in-service continuing professional education to ensure that all service providers are current and up-to-date in their understanding of pain and symptom management.

Tertiary Level/Specialist level (3)

i. All of level 2 plus:

ii. A comprehensive plan of care for the assessment and management of the patient's pain and symptoms is available, and support given to level 1 and 2 service providers in order to ensure that the plan is followed, regardless of the setting of care within a specified geographic area.

iii. All medicines of the WHO analgesic ladder, including strong opioids such as oral morphine, are available and provided as appropriate to manage the patient's pain, as part of a comprehensive programme for pain assessment and management.

iv. Level 2 service providers are empowered to provide effective management of complex pain and other symptoms.

v. There is a mechanism in place that facilitates referral for specialised interventions for control of complex pain and/or symptoms, e.g. radiation therapy, in case of spinal cord compression, bone pain or uncontrolled cancer bleeding, etc.

vi. Service providers receive and manage referrals from level 1 and 2 care providers with regards to complex pain and symptom management, referring back and providing ongoing support as required to enable the patient to receive good pain and symptom management where possible, regardless of the place of care.

vii. Training and mentorship is made available for level 1 and 2 care providers with regards to pain and symptom assessment and management.

viii. Operational research is conducted to evaluate the effectiveness of pain and symptom management.

References:

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2. Selwyn, P. and Forstein, M., Overcoming the false dichotomy of curative vs. palliative care for late-stage HIV and AIDS*, JAMA* vol.290, 2003, pp.806-814. In: Human Rights Watch (2009) "Please, do not make us suffer any more…". Access to Pain Treatment as a Human Right. USA
3. Green, K., Evaluating the delivery of HIV palliative care services in out-patient clinics in Viet Nam, upgrading document, London School of Hygiene and Tropical Medicine, 2008. In: Human Rights Watch (2009) "*Please, do not make us suffer any more*…". *Access to Pain Treatment as a Human Right*. USA
4. Pasman H.R.W and Francke A.L. Quality Indicators for Palliative Care: A systematic Review. *Journal of Pain and Symptom Management* 2009; 38 (1): 145 - 156

Standard 2.5: Management of Opportunistic Infections (OIs)

Appropriate management of opportunistic infections, including Tuberculosis (TB), improves quality of life among people living with HIV and AIDS, and those with other life-threatening illness.

Intent/Rationale

Opportunistic infections are a significant cause of morbidity and mortality among people living with HIV and AIDS. They may also be found in people with other life-threatening illnesses such as cancer. In HIV most of these infections can be prevented with appropriate prophylaxis and their incidence diminishes with the provision of highly active antiretroviral therapy (HAART).

Service providers need appropriate knowledge of screening and managing opportunistic infections because these infections are life- threatening and cause distressing symptoms including pain, but also for public health reasons such as the spread of TB.

Criteria

Primary/Basic level (1)

i. Patients with signs and symptoms suggestive of an OI, e.g. severe headache, long-standing cough, chronic diarrhoea, poor vision, etc., are identified in accordance with national or WHO guidelines.

ii. All patients presenting with HIV and AIDS are screened for TB and referred for further investigation and treatment if indicated.

iii. Patients' primary care providers are identified and educated about the possibility of the patient having an OI(s) which is a serious infection that needs referral to a health facility for appropriate investigation and medication.

iv. Treatment support is provided to patients, e.g. those on TB treatment, cotrimoxazole prophylaxis[1], diarrhoea prevention through the safe water system (SWS), malaria prevention (including giving insecticide treated mosquito nets to the patient if he/she does not have them already).

v. Treatment support is provided to patients on treatments such as radiation therapy, chemotherapy, etc., and to their main family care provider.

vi. Patients together with their care providers are referred to a level 2 or 3 service provider for treatment.

vii. Care providers have access to ongoing education and information on management of opportunistic infections.

Secondary/Intermediary level (2)

i. All in level 1 plus:

ii. Thorough assessment by history and physical examination is carried out by care providers.

iii. Referral is made for relevant investigations such as sputum analysis, cerebrospinal fluid (CSF) examination, blood tests, x-rays, biopsy, etc.

iv. Holistic management is initiated.

v. Disease-specific treatment is provided.

vi. There are appropriate referrals for in-patient care.

vii. Pharmacological and non-pharmacological treatment is given to manage symptoms.

viii. Related psychosocial and spiritual issues are addressed.

ix. Referral for eligibility to antiretroviral therapy (ART) and other specialised treatments is made.

x. Primary/secondary prophylaxis is offered as appropriate.

Tertiary Level/Specialist level (3)

i. All in level 2 plus:

ii. There is access to commencing ART either on-site or through referral, in accordance with national or WHO guidelines (most OIs occur in stage 3 or stage 4 disease, hence requiring ARVs).

iii. There is access to other specialised treatments such as chemotherapy, radiation therapy, etc.

iv. Potential overlapping toxicities, drug interactions and possible immune reconstitution are considered.

v. Alternative therapies are considered for patients in need of OI prophylaxis with previous reaction to cortrimoxazole[2].

vi. Training and supervision are available for level 1 and level 2 service providers in the management of OIs.

References:

1. Grimwade K, Swingler GH. Cotrimoxazole prophylaxis for opportunistic infections in adults with HIV. *Cochrane Database of Systematic Reviews* 2003, Issue 3.
2. Lin D, Li WK, RiederMJ. Cotrimoxazole for prophylaxis or treatment of opportunistic infections of HIV and AIDS in patients with previous history of hypersensitivity to cotrimoxazole. *Cochrane Database of Systematic Reviews* 2007, Issue 2.

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2. John G. Bartlett (2006). *Medical care of patients with HIV infection*, 9th edition. Lippincott William and Wilkins.
3. Mary Ropka and Ann William (1998). *HIV Nursing and Symptom Management*, 1st edition. Jones and Bartlett publishers.
4. Merle A. Sande and Paul A Volberding (1991). *The medical management of AIDS*, 6TH edition. W B Saunders company.

Standard 2.6: Management of Medications

Systems are in place to ensure that all patients in need of palliative care have access to appropriate and affordable medications.

Intent/Rationale

There should be access to a list of medicines for palliative care, ideally one which reflects the International Association for Hospice and Palliative Care (IAHPC) Essential Medicines list for palliative care [1] [2] [3] [4] (available on www.hospicecare.com/resources/emedicine.htm) While the essential medicines list should be adopted at a national level, it is important that there is a system in place to maintain availability of these drugs, thus avoiding interruptions of the supply of medicines to patients who need them5. Service providers need to ensure that there is access to at least one type of medicine in each category identified by the IAHPC essential medicines list. Governments need to develop plans for the implementation of palliative care and pain treatment; adopt relevant policies; introduce instruction for healthcare workers, and ensure adequate availability of morphine and other opioid medications[6]. There should be no fear of palliative care medications, and health professionals should be able to provide opiates without unnecessary concern about sanctions (including legal action) for unintended violations of laws that may inhibit the prescribing or dispensing of opiates[6]. There should be clear treatment guidelines at the national and service-provider levels[7] [8] [9] which meet the needs of both adults and children, so that appropriate medications are used and patients receive optimal doses. These guidelines should also take into account the different professional care providers available to prescribe and dispense medications, along with procedures regarding the selection, quantification, procurement, documentation and storage of medicines.

Adherence to medication is important, particularly in areas where resistance can develop if medications are not taken correctly, therefore adherence guidelines should be developed along with channels for routine communication and feedback from patients on their medications and the outcomes of treatment. It is also important to have mechanisms in place to ensure that all regulations regarding the safe storage, dispensing, administration and disposal of controlled medicines are adhered to. Ensuring quality care requires that the patient is told and understands the treatment options[10].

Criteria

Primary/Basic level (1)

i. Service providers have access to essential palliative care medications on the National Formulary (the list of drugs recognised by the ministry of health for use within a country), including both adult and child preparations, through collaboration and networking.

ii. There is sustained availability of step 1 analgesics of the WHO ladder.

iii. Resources are allocated for the procurement of essential medicines for palliative care.

iv. Documented, organised systems are in place for the selection, quantification, procurement and recording of medications.

v. Clear systems are in place to ensure an ongoing supply of medications in order to avoid interruption to the supply chain.

vi. Adequate storage facilities are available in accordance with legal requirements for the medications available, including refrigeration for medications that require it.

vii. Access to the medications storage facility is available only to authorised personnel and a robust inventory control mechanism is in place.

viii. Expiry dates for all medicines are recorded and medicines are issued based on the principle of ‘first expiry, first out’ (FEFO) or ‘first in, first out’ (FIFO). Expired and unused medicines are disposed of in accordance with national regulations.

ix. Treatment guidelines are in place stating the specific medicines, who can prescribe and dispense them, when they are used and dosages, especially for children. These are linked to the national guidelines and essential palliative care medicines available at this level.

x. Information is provided to the patient and their family by the care provider with regards to the medicine, indication, dosage, what to do if they experience side-effects, when to return for further medicines, etc. Some of this information could be included in the medicines chart (*appendix 2c*).

xi. Adherence counselling, support systems and mechanisms for measuring adherence are identified and put in place where appropriate, e.g. for TB medicines, ARVs, chemotherapy etc.

xii. Relevant care providers have access to continuing professional education regarding the safe storage, dispensing, prescribing, administration, recycling and disposal of medications.

Secondary/Intermediary level (2)

All of level 1 plus:

i. Service providers have access to all essential palliative care medicines at site or through collaboration and networking.

ii. There is sustained availability of step 1 and step 2 analgesics of the WHO ladder.

iii. There is a trained pharmacy technician or pharmacist to manage medications.

iv. Written information is provided by the care provider to the patient and their family about the medicine, indication, dosage, side-effects and what to do if they experience side-effects.

v. There are systems in place to ensure that all medicines are safely stored, dispensed, administered and disposed of in line with legal requirements.

Tertiary Level/Specialist level (3)

i. All in Level 2 plus:

ii. Service providers have access to all essential palliative care medicines.

iii. There is sustained availability of step 1, 2 and 3 analgesics of the WHO ladder.

iv. Systems are in place to support level 1 and level 2 service providers with medications as required within a specified geographic area.

v. Specialist palliative care providers and pharmacists give advice with regards to all aspects of medication management in palliative care, e.g. clinical use, selection, quantification, procurement, documentation and storage, recycling and disposal of medicines.

vi. Care providers advocate to the national ministry of health for access to essential palliative care medicine for all patients with a life-threatening illness.

References:

1. WHO (2008) *Essential Prevention and Care Interventions for adults and adolescents with HIV in Resource Limited Settings*. WHO, Geneva
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3. Merriman A (2006) *Palliative Medicine: Pain and symptom control in the cancer and/or AIDS patient in Uganda and other African countries*. Hospice Africa Uganda, Uganda
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Standard 2.7: Psychosocial Care

The psychosocial needs of the patient and family are assessed and attended to in order to improve psychological, emotional and social wellbeing of the patient, their family and carers.

Intent/Rationale

A major, neglected problem in palliative care is the under-recognition, under-diagnosis and thus under-treatment of patients with significant distress, ranging from existential anguish to anxiety and depression[1]. Measuring, documenting and managing anxiety, depression and other common psychological reactions of patients and their families, and offering a grief and bereavement care plan[2], is essential. Psychosocial care is affected by a range of cultural factors: the customs and ethnicity of patients and their families; community norms and expectations; and religious and philosophical belief systems[1]. Ensuring quality care requires that there is an appropriate range of psychosocial services available; that care is given in a compassionate way; and that it integrates physical and psychosocial elements [1].

Appropriate practical assistance is provided to help ease the social burden of the patient and family, including in social needs such as finances, social relationships, care of relatives, childcare, legal issues, food insecurity, hunger, housing and communication needs, bereavement, and spiritual and cultural issues.

Attention is paid throughout the continuum of the illness to the emotional reactions of all parties, and to the social environment in which the family lives. The interplay between the individual, family and social system is recognised and care is facilitated through effective communication and counselling.

Criteria

Primary/Basic level (1)

i. Care providers initiate conversations with the patient and their family to explore the social and emotional impact of the illness throughout its continuum, and to respond in a compassionate and empathetic manner without false comfort.

ii. Care providers recognise the need for psychological, social and spiritual support. They explore the patient's main distress at each visit and refer patients to community resources for psychosocial services[2].

iii. Care providers undertake a basic assessment of the emotional and social needs of the patient and their family, including children; provide basic support and make referrals for complex needs to be met. The assessment includes a discussion of the meaning of illness to the patient and to the family.[3]

iv. Care providers have training in basic communication, counselling skills and bereavement care, and are applying these in practice.

v. Patients and their families are accepted in their current situation and are assured of not being deserted by the care providers.

vi. There is affirmation of the patient's and family's role in care provision and their importance.

vii. Care providers know where and how to refer families for further help with social and emotional problems.

viii. Appropriate referrals are made to address complex psychosocial needs.

ix. Care providers explore available family and social support and tap into this to meet some of the psychosocial needs, in consultation with the patient.

x. Care providers explore the presence of stigma and discrimination relating to the illness within and outside the family.

xi. Stigma and discrimination are addressed by modelling respectful care and through family and community education.

xii. Patients and their families are given an opportunity to express and discuss emotional and social/practical needs such as school fees for children, legal support, and options for meeting needs are jointly identified and implemented.

xiii. The patient's and family's autonomy is maintained, including respect for their dignity and the opportunity to exercise choice.

xiv. Care providers are supported in self-awareness techniques and encouraged to use reflection to acknowledge the impact on them of working with death, dying and loss.

xv. Providers commit to regular supervision sessions and accommodate supervisory field visits.

xvi. Improving the quality of life of terminally ill patients and their families is prioritised[4].

xvii. Care providers keep records of psychosocial interventions.

Secondary/ Intermediary level (2)

i. All of level 1 plus:

ii. There are appropriately trained and qualified staff in psychosocial interventions, such as psychologists, social workers/counsellors and spiritual care providers. They provide psychosocial and practical care and advice, or supervise psychosocial care by other staff.

iii. A comprehensive psychosocial assessment is conducted and documented.

iv. The psychosocial assessment includes addressing the ways in which illness has changed the life of the individual; their coping strategies, their sources of support, and discussions of their hopes, expectations, and relationships, to identify any needs to be addressed.

v. The assessment includes information on family issues and relationships, which could be obtained using a family relationships tool such as a genogram or family tree (see *example in appendix 4b*). This captures and summarises how the family functions; the need for practical help (e.g. physical resources such as money and housing), information on daily living activities and social issues.

vi. Family meetings are undertaken to jointly discuss and manage complex family care needs, such as resolving family conflicts. A guide or checklist to conducting family meetings (*Appendix 4a*) is used.

vii. The assessment results in the prioritisation of psychosocial needs and their inclusion in the holistic care plan.

viii. The service provider is implementing a clearly designed psychosocial programme.

ix. Care providers recognise and initiate the medical treatment of psychiatric disorders such as depression.

x. Symptoms such as anxiety and anger are relieved through psychosocial support and interventions which may include psychotherapy, cognitive behavioural therapies and educational therapies.

xi. Patients experience the primary team's commitment and their genuine concern for the patient's total care[5].

xii. At each visit, care providers assess the patient's level of distress, irrespective of the setting of care, using a psychosocial or distress assessment/screening tool such as the distress thermometer as appropriate (*Appendix 5)*[1, 4].

xiii. Care providers keep accurate records on emotional and social issues for discussion in supervision, and ensure that records are kept correctly by basic level providers.

xiv. Care providers who witness extreme expressions of emotion respond in an appropriate manner with compassion and empathy.

xv. Care providers understand the family's strengths and vulnerabilities, including family traditions, norms and values[6], as these are important for care planning.

xvi. Care providers provide basic bereavement care and support. They understand the usual process of grief for adults and children, and support the family through the process.

xvii. Care providers identify complicated grief reactions and help the family to manage them or refer families to specialist bereavement support resources.

xviii. Care providers initiate programmes to raise awareness of life-threatening illness and bereavement in the community, and to educate communities on how to respond to their sick and bereaved.

xix. Care providers train, mentor and support the rest of the team, and basic and intermediary level providers.

xx. Care providers establish and maintain a database of community and other resources where patients and families can access emotional and social care beyond the organisation/service.

xxi. Service providers develop and implement a well-documented process for receiving and managing referrals for those with emotional and social support needs.

xxii. Care providers use psychological approaches which are concerned with enabling patients and those close to them to express thoughts, feelings, and concerns relating to illness[3].

Level 3: Tertiary/Specialist level

i. All of level 2 plus:

ii. Clinical practice guidelines for the management of psychosocial symptoms are developed and implemented[1].

iii. Care providers undertake a leadership role in research on the emotional and social needs of patients and families affected by life-threatening illnesses.

iv. Service providers provide consultation for complex emotional and social issues.

v. Care providers advocate for the inclusion of emotional and social issues in care and training programmes.

vi. Care providers initiate audit, evaluation and basic research in emotional and social aspects of palliative care and bereavement.

vii. Psychosocial guidelines are developed for use by level 1 and level 2 service providers.

viii. Mentorship and training is provided to level 1 and level 2 service providers.

ix. Care providers conduct regular patient/family conferences to provide information, to discuss goals of care, to offer support to patient or family, and to develop and implement comprehensive social care plans[2].

References:

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2. Pasman H.R.W and Francke A.L. Quality Indicators for Palliative Care: A systematic Review. Journal of Pain and Symptom Management 2009; 38 (1): 145 - 156
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5. Holland JC., Greenberg DB., et al (2006). Quick Reference for Oncology Clinicians: The Psychiatric and Psychological Dimensions of Cancer Symptom Management. American Psychosocial Oncology Society (APOS). IPOS Press, USA
6. Kissane D, Bylund C et al. Conducting a Family Meeting. Memorial Sloan-Kettering Cancer Center. Comskil Laboratory Council for Health Service Accreditation of Southern Africa. Hospice Palliative Care Standards. November 2004.

Other sources used:

1. Hospice and Palliative Care Association of Zimbabwe (HOSPAZ) *Palliative Care Standards, Final Draft. March 2009.*

Standard 2.8: Spiritual Care

The spiritual needs of the patient and family are assessed, and spiritual care is well-planned and coordinated in all settings.

Intent/Rationale

Spirituality is a sense of relationship to a transcendent dimension or something greater than oneself. It is a person's relationship with a supernatural being, however it is described, e.g. whether known as God, Jesus Christ, Mohammed, Buddha or simply the Supreme Being[1]. The spiritual aspects of holistic palliative care are very important and all healthcare workers can reach into the spiritual aspects of themselves to draw on the sensitivity and compassion needed to share with patients and their families what is important to them in facing chronic illness, death and grief[1]. Spiritual pain can result from the fear of dying, anger, suffering, guilt and a search for the meaning of life and purpose of living, hence the importance of encouraging patients to talk about their feelings[2] .

The patient's and family's spiritual needs, belief systems and values are addressed and respected. Spirituality can help patients cope with the uncertainty of their illness, instil hope, bring comfort and support from others, and resolve existential concerns, particularly the fear of death[1].

Spirituality is an important part of people's lives and provides a sense of connectedness and comfort during times of illness and distress[3].

Common spiritual needs, no matter what a person's belief system, include a search for the meaning of life and purpose of living, receiving and giving love, having a sense of forgiveness, hope and creativity, a sense of completion, responsibility and control[4].

Criteria

Primary/Basic level (1)

i. Care providers are able to identify the most appropriate time and space for initiating and discussing spiritual needs with the patient and the family, and provide them with information about the availability of spiritual care services[4].

ii. There is an assessment of basic spiritual needs of the patient and their family, aimed at identifying needs and providing basic support.

iii. Appropriate referral is made for complex spiritual needs to be met and there is awareness that not all existential questions can be answered by care providers.

iv. There is collaboration with spiritual care providers of all religious denominations in the community, and the patient and family have access to them if required.

v. Simple questions on spirituality such as FICA Questions[5] (*see appendix 6*) are included in patient assessment tools, and care providers are able to initiate discussions on spiritual issues.

vi. Care providers are aware that they are learning from the patient, and give time to listen.

vii. Care providers are able to identify spiritual pain, acknowledge it and ensure it is addressed by them or through referral (with consent and respect). This is documented.

viii. The patient's and family's background, beliefs, rituals and practices are respected by care providers, with no intentions to change them but to support them within their context.

ix. There is an understanding and appreciation of the wider spiritual needs of the patient and their family.

x. Care providers are aware of their own spiritual needs and are able to separate these from those of the patient.

Secondary/ Intermediary level (2)

xi. All of level 1 plus:

xii. Spiritual needs beyond the capability of level 1 service providers are identified and met on site or through referral.

xiii. Spiritual needs are incorporated in the care plan.

xiv. The patient and their family are asked what their particular beliefs and practices entail.

xv. The patient and their family have regular access to a spiritual care provider of their choice.

xvi. Care providers are aware of African religions or traditional beliefs and are willing to support the patient and their family within this context.

xvii. Care providers understand the stages of grief and have identified the patient's and family's stages of grief, and whether these have a particular link with their spirituality.

xviii. There are referrals for the management of complex spiritual needs beyond the capability of this level.

Level 3: Tertiary/Specialist level

i. All of level 2 plus:

ii. Patients have access to advanced counselling for complex spiritual needs.

iii. There is a detailed assessment for spiritual needs of the patient and their family.

iv. Care providers are able to draw together the holistic elements that impact on personal spirituality.

v. There is awareness of the need in many religions for rituals which impinge on spirituality and are necessary to bring peace. It is ensured that they are available.

vi. There is readily available access to spiritual care within the care team or a network for referring to spiritual guidance in different religions.

vii. Care providers have time for guided reflection on their own spirituality.

viii. Research and audit regarding the provision of spiritual care is undertaken.

References:

1. Waliggo JM, Gywther L. et al (2006) Chapter 16: Spiritual and Cultural Care. In Gwyther L, Merriman A, Mpanga Sebuyira L and Schietinger H. A Clinical Guide to Supportive and Palliative Care for HIV and AIDS in Sub-Saharan Africa. APCA, Uganda.

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2. Holland JC., Greenberg DB., et al (2006). *Quick Reference for Oncology Clinicians: The Psychiatric and Psychological Dimensions of Cancer Symptom Management*. American Psychosocial Oncology Society (APOS). IPOS Press, USA. Page 17

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Standard 2.9: Cultural Care

Care given to patients and their families is culturally sensitive, underpinned by respect, humility, acknowledgement and understanding of their culture and perspective[1].

Intent/Rationale

Culture refers to learned patterns of behaviours, beliefs and values shared by individuals in a particular social group. It provides people with both their identity and a framework for understanding experience. In its broadest sense, a culture is a group of people with similar ethnic background, language, religion, family values and life-views.[1]

A person's cultural roots, ethnic background, and religious and spiritual orientation will impact on their attitudes when they are struggling with a life-threatening illness. Culture has an important influence on perceptions of serious illness and death[2] and shapes beliefs about the meaning of death and the care of the sick.

Care providers understand the cultural beliefs and practices of the patient and their family and, most importantly, acknowledge and respect them. Incorporating cultural elements such as patient and family participation in decision making, the preferences of the patient and their family regarding the disclosure of information and truth-telling, language, and rituals[2] are essential to culturally appropriate care.

The goal in providing culturally competent care is to be sensitive and aware of the beliefs, practices and traditions of others and respect them when providing care. This includes self-awareness, cultural knowledge about illness and healing practices, communication skills and behavioural flexibility.

Criteria

Primary/Basic level (1)

i. Care providers ask questions which help them to understand the patient's culture and how this is influencing their responses to the illness.

ii. Patients and families are approached with respect and humility and a desire to understand their culture and perspective.

iii. Patients and their families are asked what is suitable for them.

iv. Care providers observe and understand the cultural practices of patients and their families.

v. There is collaboration with traditional healers in caring for patients, and any cultural aspects which may affect the management of patients are identified and discussed with the interdisciplinary team for further management.

vi. Patient and family rituals or traditions that surround their illness, and end-of-life and death experiences are understood and acknowledged, including religious beliefs and rituals.

vii. Care providers recognise that patient's and family's attitudes, values and beliefs may be different from their own and that those of the patient and the family are at the centre of care.

viii. Referrals are made to appropriate persons, groups or institutions and support is provided to ensure the practice of specific rituals, customs or traditions.

ix. Healthcare providers work closely with the community care provider in understanding and respecting the cultural context of the patient, family and wider community.

x. Cultural interventions are documented.

xi. There is understanding of the patient's and family's past experiences and the impact of these on the current situation.

xii. Care providers are aware that they should not impose their values and beliefs on patients and their families.

Secondary/Intermediary level (2)

All of level 1plus:

i. In partnership with the patient and family, care providers identify the cultural values that are very dear to patients and their families, and ensure that they are supported to fulfil them.

ii. Care providers are familiar with and aware of the general local cultural beliefs and customs surrounding death and dying, so that they deliver culturally sensitive services[3].

iii. Care providers are aware of their own cultural beliefs and values and how these may influence the care they give.

iv. Care providers support the person's preference for disclosure.

v. There is sensitivity to children's issues in different cultural settings.

Level 3: Tertiary/Specialist level

i. All of level 2 plus:

ii. Care providers explore, respect and support fulfilment of the patient's wishes on important personal matters, such as where the patient wishes to die.

iii. Topics on traditions and cultural beliefs are incorporated into all teaching programmes

iv. Care providers discuss with the patient and family cultural beliefs and practices that are dangerous to their wellbeing.

v. Care providers discover the uniqueness of each patient by asking questions about things such as family lifestyle, patterns of authority and communications, and expectations of care providers.

vi. Care providers give practical support in meeting the patient's and family's cultural needs.

References:

1. Waliggo JM, Gywther L. et al (2006) Chapter 16: Spiritual and Cultural Care. In Gwyther L, Merriman A, Mpanga Sebuyira L and Schietinger H. A Clinical Guide to Supportive and Palliative Care for HIV and AIDS in Sub-Saharan Africa. APCA, Uganda
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3. NASW Standards for Social Work Practice in Palliative and End-of-Life Care 2009, National Association of Social Workers, USA.

Other sources used:

1. Traditional Medicine Strategy 2002-2005, World Health Organisation
2. Canadian Hospice Palliative Care Association (2006), Training Manual for Home Support Workers
3. Marlise Richter (November 2003).Traditional Medicines and Traditional Healers in South Africa: Discussion paper prepared for the Treatment Action Campaign and AIDS Law Project - www.tac.org.za/Documents/ResearchPapers/Traditional_Medicine_briefing.pdf (Accessed June 1 2009)

Standard 2.10: Complementary therapies in palliative care

Individuals have access to complementary therapies which are evidence based and are provided in a safe and ethical manner.

Intent/Rationale

Complementary therapies, when used competently and with sensitivity, can enhance the quality of the patient's life and help their family[1]. Many patients will access them at some time or other during their illness[2]. They may not treat a specific ailment but often treat the whole person by restoring peace, balance and normal energy flow, therefore the theoretical systems on which they are based are inherent in the culture and beliefs of the people seeking treatment[3]. Patients should have the choice of whether to access complementary therapies or not, and be given information about the different complementary therapies available and how these can be accessed. Therapies should be based on a documented and evidence based procedure[4 5] and provided in an ethical and culturally appropriate manner.

Criteria

Primary/Basic level (1)

i. Care providers are able to provide basic information on complementary therapies for patients and their families.

ii. Care providers are aware of appropriate complementary therapy services in their area (i.e. where care is given through evidence based procedures and in an ethical and culturally appropriate manner) and provide information to patients about these.

iii. Referral networks are in place to complementary therapy providers to ensure that there is holistic support for the patient and their family when needed.

Secondary/Intermediary level (2)

i. All of level 1 plus:

ii. Care providers are able to provide written information on complementary therapies for patients and their families, or refer to appropriate service providers for such information.

iii. Care providers discuss issues regarding the use of complementary therapies with the patient and their families, e.g. feelings of wellbeing, end-of-life care, trying other options, etc.

iv. Any information with regards to contra-indications for complementary therapy is discussed with the patient and their family[6] .

Tertiary Level/Specialist level (3)

i. All of level 2 plus:

ii. Service providers provide some complementary therapies as part of routine palliative care for patients and their families.

iii. Advice is provided to level 1 and 2 service providers on the use of complementary therapies in palliative care.

References:

1. Marston JM (2006) Chapter 18: Complementary care. In Gwyther L, Merriman A, Mpanga Sebuyira l and Schietinger H. *A Clinical Guide to Supportive and Palliative Care for HIV and AIDS in Sub-Saharan Africa*. APCA, Uganda
2. Kellehear A (2003), Complementary medicine: is it more acceptable in palliative care practice? *MJA*; 179 (6 Suppl): S46-S48.
3. Marston JM (2006) Chapter 18: Complementary care. In Gwyther L, Merriman A, Mpanga Sebuyira l and Schietinger H. *A Clinical Guide to Supportive and Palliative Care for HIV and AIDS in Sub-Saharan Africa*. APCA, Uganda
4. Sackett DL, Rosenberg WMC, Gray JAM, Haynes RB, Richardson WS. (1996) Evidence based medicine: what it is and what it isn't. *BMJ* Jan (312):71-72.
5. Mechanick JI, Brett EM, Chausmer AB, Dickey RA and Wallach S. (2003) American Association of Clinical Endocrinologists medical guidelines for the clinical use of dietary supplements and nutraceuticals. *Endocr Pract*.;5:417-470.
6. CAMBasics (2006). National center for complementary and alternative medicine, National Institute of Health. US Department of Health and Human Services
7. Fact Sheet Number 700. www.aidsinfornet.org (accessed March 2006)

Standard 2.11: Care for special needs populations

There is holistic and coordinated care for patients with special needs and their families, through partnerships and collaboration ensuring easy access to services through a continuum of care, despite their challenging environmental circumstances.

Intent/Rationale

Special consideration needs to be given to particular groups in the community when applying standards, particularly those people who are disadvantaged or marginalised[1]. Holistic care for populations with special needs should be designed to give equitable access to quality palliative care nationwide, without marginalisation or omission of attention to special care needs in different care settings[1,2]. Special needs populations include institutionalised people such as prisoners, members of the armed forces, mentally and physically challenged people, refugees and internally displaced persons (e.g. in camps), children with a life-threatening illness or whose parents have a life-threatening illness, the elderly, religious leaders (due to expectations they won't get certain diseases), the homeless, people with substance abuse problems, and closed or difficult-to-reach communities such as remote tribes. The issues affecting incarcerated, institutionalised and displaced people are more traumatising, with higher risks of rights abuses, HIV infection and limited access to palliative care [3]. It is important that there is attention to the needs of traditionally medically under-served patients: those with little English proficiency or illiterate, for whom care at the end of life is particularly difficult because communication is limited, and patients with chronic mental illness or limited education[4].

It is important to recognise that people with special needs will be present across all identified patient populations and do not represent distinct and separate groups in the community[1]. An effective communication strategy is needed for special needs populations, to cater for their distinct needs. Communication links must be established with communities in institutions for special populations, such as health care staff, administrators and community members such as prisoners. These people need to die with dignity, with access to family[5] and peers for psychological support. For some people, their current place of residence such as a prison will be their last home, therefore there is need for them to access services in that setting.

Special needs could hinder access to care because different needs may require addressing by different service providers. There are also perceptions that compassionate care cannot take place in certain environments such as prisons, and there is a lack of prioritisation for planning and budgeting for palliative care services in institutions for special needs populations. Yet people with special needs are human beings, deserving a dignified and loving environment[3].

There is a need for advocacy for better care, end-of-life care and rights observation among special needs populations with respect to social cultural norms in those groups.

Criteria

Primary/Basic level (1)

i. Service providers understand and accept the circumstances of patients with special needs and their families, and establish trusting relationships with them.

ii. There is partnership between institutions of special needs populations and palliative care services to achieve optimal patient outcomes, as well as partnership with the wider social services sector to meet the needs of patients and their families[1].

iii. Services are flexible enough to meet the needs of potentially highly vulnerable patients, such as the homeless.

iv. Care providers have basic communication skills training which incorporates the handling of patients and families with special needs.

v. Care providers are encouraged and supported in self awareness techniques to identify prejudice and bias against special needs populations and what they can do with this, such as seeking supervision.

vi. Socially and culturally appropriate means of managing the care of special populations are used, such as involvement of peers. Inmates and army officers can be peers to each other, or cultural leaders, translators, etc. can be used.

vii. There is understanding that life-threatening illnesses do not discriminate but affect all populations (e.g. religious leaders[6] *can* be infected by HIV).

viii. There are disclosure counselling guidelines for special populations. Despite their mobility and mentally status, patients are afforded right-to-know diagnosis and prognosis, to aid their seeking care from relevant providers and mobile service points.

ix. There is careful attention to the decision-making and care delivery process, which is supported by other agents such as authorised guardians, while keeping the needs of the patient as the primary focus. Patients are given the opportunity to contribute as far as they are able to the care planning and decision-making process.

x. There is documentation of legal needs and interventions among special needs populations.

Secondary/Intermediary level (2)

i. All of level 1 plus:

ii. Models of service delivery include a mobile component to cater for mobile populations such as outreach points, wellness centres [7, 8].

iii. Standard operating guidelines for the delivery of palliative care include special needs populations.

iv. Service providers accommodate special needs and provide access to basic equipment such as wheelchairs, crutches, etc.

v. There are partnership agreements between service providers and institutions for special needs populations (army, prisons, camps, etc.), for supportive collaborations in care provision.

vi. There is a plan for community support for the reintegration of released prisoners and displaced persons, covering treatment, adherence, psychosocial support and links with local peer support and faith-based organisations.

vii. There is support for the formation of peer special needs groups which offer peer support on legal issues and take a role in advocacy for special needs.

Tertiary Level/Specialist level (3)

i. All of level 2 plus:

ii. There are training programmes which include the provision of palliative care to special needs populations.

iii. People with special needs have access to specialist palliative care services.

iv. Institutions of special needs populations are being supported to develop palliative care programmes within their institutional healthcare programmes through adopting the holistic care approach, using an inter-disciplinary team, linking with community services, providing families with support, and building institutional capacity for palliative care service provision.

v. There is holistic care which includes pain and symptom management, use of an inter-disciplinary care team, support for compassionate release where appropriate, expanded family visitation policies, and psychosocial and spiritual care.

vi. There is a network database or directory which assists referrals for people with special needs to access services.

vii. Care providers assist patients in identifying their current case management needs, developing a plan for life after their institutionalisation, and detailing medical and other needs and how these should be met[3].

viii. Care providers help to implement the care plan once patients are discharged from the institutions, and maintain contact with patients and their families during the transition to new locations or back into society.

ix. There are communication links within the institutions for special needs populations, among professional care providers, other administration staff and the institution community, as well as with outside community and public health agencies.

x. Patients are supported to meet needs such as housing, healthcare, employment, rehabilitation services, emotional and spiritual support, transportation, legal services, food, clothing and family support. These needs can be overwhelming among special needs populations.

xi. There is information on and contact details for specialists to cater for patients with special needs and their families on referral.

xii. There is publishing of practice issues on service delivery for special needs populations8.

xiii. There is continual assessment of palliative care delivery models of care, such as outreach that is tailored to highly mobile at-risk groups.

xiv. There is strategic planning for special needs populations' palliative care at institutional and national level, such as end-of-life care programmes in prisons3, outreach for displaced populations, etc.

xv. There is strategic networking, with level 3 service providers playing a role in the integration of legal, ethical and human rights issues into work of partners in the area of special needs populations8.

xvi. There is documentation of best practices in palliative care for special needs populations.

xvii. There is involvement in the development and implementation of special palliative care delivery models for prisons, the military and other special situations.

xviii. Service providers advocate for increased access to palliative care by special needs populations.

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Standard 2.12: End-of-life care

Care is provided at the end of life for the patient and their family so that the patient is made as comfortable as possible and their dignity preserved.

Intent/ Rationale

It is important that care providers are able to recognise the terminal phase of illness, as all patients with a life-threatening illness, e.g. HIV and AIDS or cancer, will eventually reach the end of their life. The aim of end-of-life care is to enable the patient to die in peace and dignity and to support them to plan ahead and say their farewells. Last-minute panic from the family should be avoided to enable the patient to die in peace and dignity. The most appropriate end-of-life care should be negotiated with the patient and their family, including setting realistic goals[1].

Approaching death brings reconsideration of death/after-life issues; it also becomes a time for identifying values, beliefs and personal resources. Mental health professionals, social workers and pastoral counsellors must be available to patients at the end of life because of the pronounced, complex distress many experience[2].

Development of clinical practice guidelines relating to psychiatric, psychosocial and spiritual domains has the potential to enhance end-of-life care in a major way. Management of several physical symptoms that are common at the end of life (e.g. pain, fatigue, nausea and vomiting and dyspnea[2]) is equally important. A key concept in end-of-life care guidelines is the recognition that the physical and the psychosocial, existential and spiritual concerns are interrelated and overlapping, so it is critical that the patient experience equal attention to all. Central to quality of all care at the end of life is communication between the doctor, patient and their family[4].

Criteria

Primary/ Basic level (1)

i. Care providers are given basic education and training in end-of-life issues[2].

ii. Basic physical support for the dying patient and their family is provided within their preferred setting.

iii. Provision is made to enable the patient and their family to participate in customary or religious end-of-life rituals that have meaning for them.

iv. Basic spiritual and social support is provided by the community to the patient and their family.

v. There is a close working relationship with level 2 and 3 service providers to ensure that the patient dies in peace and dignity.

Secondary/Intermediary level (2)

i. All of level 1 plus:

ii. Symptoms in the dying patient are assessed, documented and managed.

iii. Treatment and care are based on the wishes of the patient and their family.

iv. The patient and their family are given information about the signs and symptoms of approaching death in a manner appropriate to their individual needs and circumstances.

v. End-of-life issues and the anticipation of the death of the patient are honestly discussed in a socially and culturally appropriate manner.

vi. Immediately following the death of the patient and during the early bereavement phase, families and caregivers are given time and support to assist with adjustment to the loss of their loved one.

vii. There is a close working relationship with level 1 and 3 service providers to ensure that the patient dies in peace and dignity.

Tertiary Level/ Specialist level (3)

i. All of level 2 plus:

ii. Care providers are given advanced education and training in end-of-life issues[2].

iii. Specialist advice is available for care providers with regards to managing challenging symptoms and situations in caring for a dying person.

iv. A close working relationship with level 1 and 2 service providers is maintained to ensure that the patient dies in peace and dignity.

v. There is a well-documented referral process for ensuring continuity of care for the dying person wherever they may be cared for.

vi. Guidance and support is available to any care provider who needs advice about ethical dilemmas related to end-of-life care and decision making.

vii. Debriefing is available for all care providers.

viii. The service takes a lead on establishing good practice for end-of-life care, and teaches others how to provide end-of-life care.

ix. Advocacy is undertaken for good end-of-life care to become accessible to patients dying in hospitals.

x. There is a clear system for the evaluation of end-of-life care, which includes attention to the management of distress[2].

References:

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Standard 2.13: Grief, loss and bereavement care in adults

The patient, their family and care providers have access to grief, loss and bereavement support based on their needs and context.

Intent/Rationale

Grief begins as soon as a loved one develops symptoms perceived as life-threatening, rather than beginning only at the person's death[1]. The quality of care and support that the patient receives creates powerful memories and affects the bereavement of those who are left[2].

Caring for the bereaved is a responsibility and a privilege. In AIDS-related deaths, the bereaved face significant issues that can complicate their grief process. Interventions that incorporate a holistic approach to grief and loss can facilitate the bereavement process, possibly improving the bereaved person's ability to function, reducing some of the pain experienced and providing an opportunity for transformation[1].

Grief is highly individualised, depending on the person's perception of the loss, and influenced by its context and concurrent stressors[1].

Recognising and documenting the transition to the active dying phase, ascertaining and documenting patient and family wishes about the site of death, and implementing a bereavement care plan[3] are essential for quality of life. Recognising and treating distress in the family, including the management of bereavement after death of the loved one, are also important[4].

Criteria

Primary/Basic level (1)

i. Information about loss and grief and the availability of bereavement support is available to the patient and their family.

ii. Information about completing bereavement tools, e.g. memory books/boxes should be provided to families prior to the death of a family member, and support given to use these.

iii. Basic assessment is undertaken on how well the family is coping with regards to the illness and death of a loved one and referral made for more intense support if required.

iv. Care providers are regularly asked how well they are coping with regards to the illness and death of patients, and support is provided if necessary.

v. Care providers have an understanding of the expected emotional reactions to living with a life-threatening illness and loss, and are able to explain and normalise this process with the family.

vi. Care providers educate the family and community about issues relating to death, dying and bereavement.

vii. Care providers are trained in basic bereavement care and understand the usual process of grief.

viii. Care providers identify complicated grief and have access to resources to refer families experiencing complicated grief reactions.

ix. Care providers have information on, access to, and are able to mobilise community support groups that may complement their work in assisting the terminally ill or bereaved.

x. Care providers understand the feelings and emotions associated with grieving and support the patient and family thorough this process.

xi. Care providers explore and respect the wishes, beliefs and practices associated with grief, loss and bereavement of the patient and family and the wider community.

xii. Care providers understand the traditional rights of succession in families and communities they are serving and how these impact on the patient.

xiii. Care providers are aware of and deal with their own grief separately from that of the patient and family.

Secondary/Intermediary level (2)

i. All of level 1 plus:

ii. Good referral and support systems are in place between level 1, 2 and 3 service providers so that emotional and bereavement support is provided to those who need it.

iii. Providers are trained in comprehensive bereavement care and understand the usual process of grief for adults. They are able to explain this to the family and support the family through the process.

iv. Providers identify complicated grief reactions and help the family to manage them as far as possible. They are able to identify when to refer families to specialist bereavement resources.

v. Providers have information on and access to community support groups that may complement their work in assisting the chronically ill or bereaved. They are able to advocate for community support for these groups and to design support programmes.

vi. Providers initiate programmes to raise awareness in the community of chronic illness and bereavement and to educate communities in how to respond to their sick and bereaved.

vii. Providers are able to initiate audit, evaluation and basic research in emotional and social aspects of palliative care and bereavement.

Tertiary Level/Specialist level (3)

i. All of level 2 plus:

ii. Guidelines are developed and available for providing grief and bereavement support to the patient, their family and care providers.

iii. Care providers have advanced training in grief, loss and bereavement.

iv. Care providers undertake a comprehensive assessment of grief and bereavement needs and manage complex needs.

v. Care providers receive and manage complex grief and bereavement referrals from level 1 and 2 service providers and provide these levels with support when needed.

vi. Service providers have a bereavement programme with a designated coordinator.

vii. The bereavement programme focuses on: addressing practical issues such as food, accommodation and care for the patient's children; identifying and legitimising feelings of sadness, anger, guilt and anxiety; encouraging expression of feelings in privacy; enabling completion of unfinished business; encouraging living full and enjoyable lives whenever possible, and engaging patients and care providers in life review, for example through memory books.

viii. Care providers understand the stages, phases and tasks of grief and bereavement (i.e. accepting the reality of the loss, experiencing the pain of grief, adjusting to the loss and reinvesting energy away from the deceased into new life) and support the patient and family through these.

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Standard 2.14: Ethical care, human rights and legal support

The care given observes the ethical principles of autonomy, beneficence, non-maleficience and justice; upholds the human rights of the patient and their family and ensures support in meeting legal needs.

Intent/Rationale

Every individual is unique and should have equal access to palliative care, irrespective of the family's financial status or where they live. Various countries have Patients' or HIV and AIDS Charters which set out the rights of all patients and their families[1 2]. The best interests of the individual should be the primary consideration in all decision making and decisions be made through an ethical decision making process[3]. Every individual has the right to receive adequate pain relief and symptom management and should be treated with dignity and respect and be afforded privacy[4]. Health service providers have legal responsibility towards their patients and should exercise the mandated responsibility to support decision making on patient involvement in their own care, end-of-life care and a good death with dignity in regard to the individual's social cultural context.

Both palliative care and human rights are based on the principles of the dignity of the individual and the principles of universality and non-discrimination. To palliative care personnel, this creates a self-evident premise that palliative care is a human right[5]. The human rights approach to advancing palliative care development emphasises the fact that care of patients with life-threatening illness is a fundamental responsibility of governments, society and health professionals[6].

Ethical and legal aspects of care (e.g. documenting patient preferences for goals of care, treatment options and the setting of care; making advance directives and promoting advanced care planning[7]) are important in palliative care provision. Palliative care providers are in a good position to discuss legal issues with people living with HIV and AIDS[8] and those with other life-threatening illnesses.

Because of the wealth of available knowledge, all countries can in theory, at some useful level, implement the four basic components of cancer control – prevention, early detection, diagnosis and treatment, and palliative care – and thus avoid and cure many cancers, as well as palliating the suffering[9]. Palliative care is an urgent humanitarian need worldwide for people with cancer and other chronic fatal diseases. Palliative care is particularly needed in places where a high proportion of patients present in advanced stages and there is little chance of cure[9].

Criteria

Primary/Basic level (1)

i. Care providers are given basic training and information on patient's rights, child rights, gender, legal and advocacy issues in palliative care.

ii. Care providers know and understand the rights of the patient and their family along with their organisation's responsibilities as identified in laws, charters and regulations.

iii. Care providers work collaboratively with the community served in order to effectively protect and advance the rights of the patient.

iv. The rights of the patient and their family are made known to them in a language and form they can understand.

v. Where there are language and cultural barriers preventing the patient from asking questions and expressing their concerns, an interpreter who is trained for this role and in respect for confidentiality is available to assist[3].

vi. Where the patient is unable to understand his or her rights, a mechanism is put in place to ensure that his or her family care providers are included in the process of protecting these rights.

vii. The patient and their family are enabled to participate in care decisions through the provision of sufficient information on the care and treatment proposed.

viii. There is a trusting relationship between the care providers and the patient. Informed consent, confidentiality and truth telling are observed, promoted and documented[3].

ix. All patients who qualify for palliative care receive equal access to services irrespective of gender, sexual orientation and social status.

x. Support is provided to the individual and their family to protect their rights to participate in the care process.

xi. There is a process in place to identify and respect the values and beliefs of the individual and their family.

xii. The need for legal planning assistance is identified and support offered to meet needs such as Will-making, succession planning and access to social benefits and entitlements.

xiii. The patient is referred or linked to the institution, community social worker or welfare officer for access to legal support and planning.

xiv. There is collaboration, networking and referral to legal services and human rights services to meet needs beyond the capability of this level.

xv. Where applicable, patients and their families are referred or linked with free or subsided legal support services.

xvi. There is documentation of legal needs and interventions through methods such as activity reports.

Secondary/Intermediary level (2)

i. All of level 1 plus:

ii. The service provider has a clearly defined consent process described in policies and procedures which can be shared with level 1 services as appropriate.

iii. There is a qualified professional care provider whose primary role is to advocate for the rights and needs of patients and their families.

iv. Legal support is provided within the national or local framework.

v. Legal aspects of care are included in the care plan.

vi. Plans and forms for the referral of patients to appropriate health specialists include referral for legal advice, advocacy services and guardianship boards[10].

vii. There is a plan or system for death certification.

viii. There is a monitoring and an evaluation plan that incorporates ethical care, human rights and legal support indicators and outcomes.

ix. There is an information-sharing strategy within the institutional forums, such as multi-disciplinary team meetings and report dissemination to statutory guardians and other stakeholders involved in care.

x. Clinical protocols for service providers include legal responsibility and health risk assessments of their patients.

xi. There are resources and materials on human rights standards in relation to palliative care.

Tertiary Level/Specialist level (3)

i. All of level 2 plus:

ii. There is a palliative care advocacy strategy in line with international human rights frameworks and national standards [10, 11].

iii. Care providers participate in the development of national guidelines on palliative care, and ensure that human rights and legal aspects of palliative care are included.

iv. There is strategic networking where service providers play a role in the integration of legal, ethical and human rights issues into the work of other partners[12].

v. There is documentation of best practices in relation to ethical care, human rights and legal support.

vi. Service providers develop and offer tailored training courses on legal support and human rights issues in palliative care.

vii. There is formal collaboration with legal service providers and human rights organisations, which are given basic training in palliative care.

viii. Advice is provided to level 1 and 2 service providers with regards to ethical care, human rights and legal support, and how these can be implemented into palliative care practice.

ix. Mentorship and training is made available for level 1 and 2 service providers in ethical care, human rights and legal support.

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Standard 2.15: Clinical Supervision

Clinical supervision is provided to care providers working in palliative care.

Intent/Rationale

Clinical supervision is an important part of palliative care practice. It enables care providers to receive professional supervision by and support from a skilled supervisor to help them improve patient care, through identifying solutions to problems, increasing understanding of palliative care, improving standards of care, developing their skills and knowledge and enhancing their understanding of their own practice[1]. Supervision should be provided by a trained palliative care provider who is also trained to provide supervision. Supervisors are selected for their ability to listen, assess and coach in terms of personal and professional development issues. Supervision sessions should, where possible, be provided on a one-to-one basis, be documented and include information on workload, challenges, personal/professional development, self awareness to identify personal shortcomings, vulnerabilities, strengths.etc., along with any relevant personal information that could potentially affect the individual's work[2].

Criteria

Primary/Basic level (1)

i. The clinical supervision needs of professional and non-professional care providers are identified and acknowledged by management.

ii. Basic clinical supervision needs are addressed by the service. If this is beyond service capability, there is a documented mechanism for having these needs met.

iii. Those providing supervision have relevant qualifications and experience.

iv. Regular documented supervision sessions are held, and may be one-on-one or group supervision.

v. The care provider is aware of who their clinical supervisor is and what their role is.

vi. The clinical supervisor has been identified, is aware of their role as supervisor and has access to further support as required.

vii. Care providers report that the clinical supervision is beneficial and helpful to their practice.

Secondary/Intermediary level (2)

i. All of level 1 plus:

ii. Clinical supervision is provided to level 1 service providers as appropriate.

Tertiary Level/Specialist level (3)

i. All in Level 2 plus:

ii. Weekly clinical meetings are scheduled involving the entire clinical team.

iii. Professional consultation by qualified personnel is available to care providers at all hours[3] and they know how to access it.

iv. Supervisors receive ongoing supervision and training.

v. Clinical supervision is provided to level 1 and 2 service providers as appropriate.

References:

1. Nursing and Midwifery Council (2006) *A-Z advice sheet: Clinical Supervision*. NMC, London.
2. Royal College of Nursing (2003) *Clinical supervision in the workplace: Guidance for occupational health nurses*. RCN. London
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Standard 2.16: Inter-disciplinary Team

Team-work is an integral part of the philosophy of palliative care[1] and inter-disciplinary teamwork is an essential component for the provision of high quality and comprehensive palliative care.

Intent/Rationale

An inter-disciplinary approach is essential if complex and often competing needs of the patient and the different family members are to be met.[2] Cross-functional, inter-disciplinary teams offer specialist areas of care and benefits to patients and practitioners. In many settings however, multi-disciplinary teams may be the practical limit of teamwork.[2]

The needs of individuals receiving palliative care are many, including physical, emotional, social, spiritual and cultural needs. The provision of high-quality palliative care requires an inter-disciplinary team which includes professional and community care providers. Teamwork involves care providers with different skills working together to provide holistic care to patients and families, including children, facing illness and bereavement.

The inter-disciplinary team works together to co-ordinate a holistic plan of care with the patient and family at the centre of care. This is based on a holistic assessment of the needs.

Teamwork presents an opportunity for genuine consultation and collaboration and offers great benefit to patients and care providers, through the opportunity to get support and wisdom from diverse colleagues.[2] To meet patients' needs for psychological, social, and existential, religious or spiritual concerns, the primary treatment team should include (or have available to it) a psychosocial team that consists of a social worker, a mental health professional and a pastoral counsellor[3].

Criteria

Primary/Basic level (1)

i. The core team comprises nurses, doctors and community care providers who may be on site or accessed through a network and referral system.

ii. Effective channels of communication are in place within the caring team and with all others involved in patient and family care.

iii. Care providers receive regular supervision.

iv. Team members identify the patient's and family's physical, social, emotional and spiritual needs through basic assessment and management, and refer complex needs to levels 2 and level 3 for advanced management.

v. Basic holistic care is provided.

vi. There is evidence of optimal use of community resources, including community care providers and support groups.

vii. The main family care provider for the patient and significant others are identified jointly with the patient and are involved in care provision.

viii. Family care providers and family members are supported with education, information, emotional and practical support in relation to their care role.

ix. Family care providers are encouraged to practise self-care activities to minimise stress and promote their wellbeing and safety.

x. Family care providers are provided with information about relevant service providers who may be helpful.

xi. Team members treat each other in a respectful and professional manner[5].

xii. Team members demonstrate a common purpose and understanding of each others' role and are able to pool resources [5].

Secondary/Intermediary level (2)

i. All of level 1 plus:

ii. The core team has skills in different areas of care and consists of a nurse, doctor, social worker/counsellor, spiritual care provider and community care providers on site.

iii. There is access to other specialist skills such as psychologists, physiotherapists, occupational therapists and other staff through referral according to the patient's needs.

iv. Members of the community are given an opportunity to contribute to the development of care systems and services.[2]

v. Team members have had an introduction and orientation to palliative care.

vi. Team members have access to support to enhance their palliative care skills.

vii. The team uses a palliative care approach incorporating a concern for the holistic needs of the patient and family members as well as other care providers.

viii. The team is composed of healthcare personnel specially trained in palliative care.

ix. Support and capacity-building for other relevant stakeholders is ongoing.

x. The team has regular meetings for planning, monitoring and evaluating patient care.

xi. There are mechanisms for the supervision of team members, and records are kept.

xii. There is clear role definition and respect for each others' roles, as well as clear reporting lines.

xiii. Leadership is task-dependant, with tasks defined by the individual patient's situation[6].

Tertiary Level/Specialist level (3)

i. All of level 2 plus:

ii. There is effective multi-disciplinary and inter-disciplinary working within specialist teams, and coordination across a wide range of professions to ensure that all patients can access services[7].

iii. Social workers, mental health professionals and pastoral counsellors are available to provide the consultation and treatment that would benefit patients and their families when the severity of distress exceeds that readily managed by the primary team [3].

iv. There is access to additional specialists such as psychologists, physiotherapists and occupational therapists.

v. Teams work in partnership with those providing generalist palliative care to ensure that patients' and families' complex needs are met.

vi. All team members, including specialists, are trained in palliative care.

vii. Team members are aware of professional boundaries, and understand and value the roles and responsibilities of other team members.

viii. Regular inter-disciplinary team meetings are held to discuss the care of new and existing patients.

ix. There are policies and procedures for the provision of support to the team, including conflict resolution and annual team-building activities.

x. Networks and formal agreements are in place to ensure that identified needs of care providers are met.

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Standard 2.17: Providing support to care providers

There is a system for providing support to care providers.

Intent/Rationale

Staff, volunteers and family members who are engaged in the provision of palliative care experience loss, suffering and exhaustion on an ongoing basis. Carers themselves therefore require support to enable them to continue to provide quality patient-centred holistic care that addresses physical, social, emotional and spiritual needs. Support to care providers can be in two forms: formal and informal. A health organisation is one which is able to acknowledge the presence of an emotional agenda and recognises that this will operate at both a conscious and an unconscious level. It will also be able to work creatively with the emotion generated by the nature of the work, and the internal tensions within the organisation and the individual, and thus continue to stay engaged with the main task of the organisation and support its care providers in doing the same[1].

Working closely with dying people can put a person in touch with previous loss experience and reawaken unresolved grief, which may affect how they relate to the person being cared for in the present[1]. The fact that some of those providing care are themselves HIV positive, with similar needs to their patients, means that the need for support is even more important[2].

Failure to recognise and address the emotional and psychological problems of working in palliative care causes much of the staff stress and team difficulties that arise over time.

Criteria

Primary/Basic level (1)

i. Care providers receive initial and ongoing training and support.

ii. Care providers are taught and equipped to practise infection control.

iii. Care providers have access to professional supervision.

iv. There is a mechanism for expression of feelings by the care providers following the loss of a patient[1].

v. Care providers meet together to develop and maintain a team identity, and maintain contact and communication through monthly meetings based on honest and constructive sharing.

vi. There are care provider support groups and there is time and space for meeting to discuss issues affecting the team.

vii. Care providers recognise the value of team working.

viii. Care providers are willing to talk to their colleagues about their stress, and are interested in supporting each other in dealing with stress.

ix. Care providers have personal coping strategies based on their belief systems, lifestyle management and family support.

x. There is recognition that staff support is an essential component of palliative care.

Secondary/Intermediary level (2)

i. All of level 1 plus:

ii. Care providers are selected according to established guidelines.

iii. A ‘Care of the caregiver’ programme includes activities aimed at stress management.

iv. Employed caregivers have access to regular and documented debriefing sessions.

v. Workload and hours of work are monitored. All care providers take leave regularly and have manageable quantities of work.

vi. There is support for care providers in multitasking, balancing priorities and meeting of contradictory demands.

vii. Care providers know and understand the nature of their own responses to other people in order to maintain a professional relationship and role[1].

viii. There is a formal process of professional support (clinical supervision) and learning to enable care providers to develop knowledge and competence and assume responsibility for their own practice.

ix. Routine team meetings are held to provide care providers with an opportunity to debrief or address any issues relating to their work and team functioning.

x. Care providers are encouraged to acknowledge personal problems or crises and seek help and support from within or outside the team.

xi. Care providers recognise and acknowledge conflict, understand its causes and use healthy methods of conflict resolution, such as removing symptoms of it and clarifying who should be involved in achieving agreed outcomes.

xii. There are good organisational and personal coping strategies to deal with work-related stressors, including team support.

xiii. There is appropriate management of the transition from work roles to social roles, e.g. at work social events[1]`.

Tertiary Level/Specialist level (3)

i. All of level 2 plus:

ii. Care providers have access to personal supervision.

iii. A documented 'Care of the caregiver' programme is in place.

iv. Self-care and working as a member of a team are included in the orientation programmes of all care providers.

v. Stress levels in care providers are monitored and recorded.

vi. Care providers are rotated among different patients to avoid constant maximum exposure to grief and loss.

vii. Research is conducted related to care provider burnout and compassion fatigue.

viii. There are guided team meetings focusing on discussing team functioning.

ix. There are clear team expectations.

x. Team-building and support activities are incorporated in annual plans and budgets.

xi. Care providers are involved in social support for one another, in decision making and work planning, and exercise some control over their workload[1].

xii. Care providers have access to an outside professional for support with emotional and psychological issues if required[3].

xiii. There are policies which encourage care providers to take time off to prevent burnout.

xiv. There are debriefing sessions for care providers following the death of challenging patient cases.

References

1. Speck P. (2007). Maintaining a healthy team. *Teamwork in Palliative Care: Fulfilling or frustrating?* Oxford University Press. New York. USA
2. Cameron S, Coetzee L, and Ngidi N (2009). Community Caregivers. In: Gwyther L, Bethke E, Brouard P and Sephton S (eds). *Legal Aspects of Palliative Care*. Hospice Palliative Care Association of South Africa and Open Society Institute/ Open Society Foundation South Africa. www.hospicepalliativecaresa.co.za
3. Twycross R (2003). *Introducing Palliative Care*. Fourth Edition. Vuc Litho. South Africa

Princible 3: Children's Palliative Care

Introduction to the principle:

Children's palliative care aims to improve the quality of life of children with a life-threatening illness, through a holistic approach including the control of pain and symptoms[1]. Meeting the palliative care needs of children requires a comprehensive and integrative approach from a skilled multi-disciplinary team[2] at the different levels of care provision. While there is significant overlap between adult and children's palliative care, there are significant differences[3] and children are not just 'little adults', e.g., communication with children tends to be more difficult than with adults and the method of action of drugs in children differs from that in adults. In end-of-life care there are subtly different challenges facing professionals dealing with dying children, and these require well-structured support and development systems. Children tend to have a broader range of people involved in their care, and so team-working and an understanding of team dynamics is especially important. Children's palliative care in Africa presents challenges due to the high number of children requiring care[4] along with child-headed households. Due to the significant overlap between adult and children's palliative care, many of the standards defined in 'Principle 2: Holistic Care Provision' are also applicable to children's palliative care and have not been repeated here.

Standard 3.1: Holistic care provision in children

Children's palliative care is provided by a multi-disciplinary team throughout the course of the illness and in the family's preferred environment.

Intent/Rationale

Palliative care for children should be provided across the continuum of care, from diagnosis through to death and bereavement. Palliative care should be given alongside treatment that is aimed at cure or prolonging life and ideally should be provided wherever the child and family choose to be, e.g. in the community, in the town, in the hospital etc. (although this is not always feasible). Where possible, families should be able to move between locations without the care of the child being compromised, therefore strong referral networks are needed between all levels of service delivery[5].

Criteria

Primary/Basic level (1)

i. The unit of care is the child and their family.

ii. Professional care providers have received basic training on the principles, objectives and practices of palliative care for children.

iii. Community care providers are supervised by a professional care provider who has had basic training in the principles, objectives and practices of palliative care for children.

iv. The palliative approach is adopted by professional care providers incorporating a concern for the holistic needs of the child, including the needs of the family, and is based on an open and receptive attitude towards death and dying.

v. Families refer themselves to level 1 service providers for support with the care of their child.

vi. One person from the service provider is identified as the family's key worker and contact person[6].

Secondary/Intermediary level (2)

i. All of level 1 plus:

ii. Palliative care for the child and their family is provided by an inter-disciplinary team of health providers who have been trained and are knowledgeable and skilled in children's palliative care.

iii. There are appropriate links between different levels of service provision to enable the child and their family to access expertise, irrespective of the geographic location or size of the service.

Tertiary Level/Specialist level (3)

i. All of level 2 plus:

ii. The provision of palliative care to the child is supervised by a specialist children's palliative care provider.

iii. The composition of the team providing palliative care for the child and their family includes specialist palliative care providers as well as specialist children's care providers, drawn from a range of disciplines that will enable the service to meet the cultural, physical, psychological, social and spiritual needs of the child and their family.

iv. The team's expertise in children's palliative care helps to inform education, training and research as well as practice, and is shared where possible with level 1 and 2 service providers.

v. Mentorship and training is provided to level 1 and 2 service providers.

vi. The team of carers providing for the child and their family are provided with psychosocial support and supervision, and where required will offer this service to level 1 and 2 service providers.

References:

1. World Health Organisation (2002) Palliative care. www.who.int/cancer/palliative/definition/en/ (Accessed July 2009)
2. EAPC (2007) IMPaCCT: *standards for paediatric palliative care in Europe*
3. Lenton S, Goldman A, Eaton N and Southall D. (2006) Development and epidemiology, In: Goldman A, Hain R and Liben S (Eds) *Oxford Textbook of Palliative Care for Children*. Oxford University Press, Oxford.
4. Amery J, 2009; Introduction; In: *Children's Palliative Care in Africa*; Amery J; Oxford University Press, London. In print.
5. Adapted from EAPC (2007) IMPaCCT: *standards for paediatric palliative care in Europe*.
6. Hynson JL (2006) The child's journey: Transition from health to ill-health. In: Goldman A, Hain R and Liben S (Eds) *Oxford Textbook of Palliative Care for Children*. Oxford University Press, Oxford.

Standard 3.2: Pain and Symptom Management for Children

Every child requiring palliative care has access to pharmacological, psychological and physical management of pain and other symptoms, 24 hours a day, 365 days a year.

Intent/Rationale

The general principles for pain and symptom management in children requiring palliative care include:

a) Treatment of reversible conditions

b) Palliation of symptoms

c) Relief of distress for both parents and children.

These are all considered essential and, where possible, the cause of any symptoms is treated alongside managing the symptoms1. Assessment is a prerequisite to good pain and symptom management. The management of pain and symptoms in children follows the similar guidelines for adults, e.g. using the WHO analgesic ladder and ensuring that pain relief is provided by the clock, by mouth and by the child[2]. It is important to note that oral morphine can be used safely in pain management for children[3 4].

Criteria

Primary/Basic level (1)

i. Community care providers undertake a basic assessment of the child's pain and symptoms and seek help or advice when needed.

ii. Professional care providers undertake a basic assessment of the child's pain and symptoms, and provide basic pain and symptom management.

iii. There is routine access to step 1 analgesics, and to step 2 and 3 analgesics under the guidance of level 2 and 3 service providers.

iv. Care providers have clear instructions about the ongoing management of the child's pain and symptoms, and know when to refer to level 2 and 3 service providers.

v. There are written instructions for managing pain 'by the clock' and for giving breakthrough analgesics as required.

vi. The care providers have clear instructions about how to seek help from level 2 and level 3 service providers if needed, in particular out of normal working hours.

vii. Non-pharmacological as well as pharmacological methods of pain and symptom management are provided.

viii. Referral networks are in place to level 2 and 3 service providers to ensure that there is clinical support for the child when needed.

Secondary/Intermediary level (2)

i. All of level 1 plus:

ii. Professional care providers undertake a comprehensive assessment of the child's pain and symptoms.

iii. Effective pain and symptom management is provided.

iv. There is routine access to step 1 and step 2 analgesics, and step 3 analgesics under the guidance of a level 3 service provider.

v. There is an inter-disciplinary team available to support the assessment and management of the child's pain and symptoms. This includes the treatment of the underlying cause of any symptoms as appropriate, alongside the management of that symptom.

vi. Side-effects of medications are anticipated and actively treated as appropriate.

vii. Referral networks are in place to level 3 service providers to ensure that there is clinical support for the child when needed.

Tertiary Level/Specialist level (3)

i. All of level 2 plus:

ii. A comprehensive plan of care for the assessment and management of the child's pain and symptoms is developed.

iii. Support is given to level 1 and 2 service providers in order to ensure that the plan of care is followed regardless of the setting of care.

iv. Step 3 analgesics are provided as appropriate to manage the child's pain as part of a comprehensive programme for pain assessment and management.

v. There is access to paediatric formulations of medications and a clear system in place to enable the child to access these formulations regardless of the place or level of care.

vi. Complex pain and symptoms in children are assessed and effectively managed.

vii. Leadership regarding the provision of pain and symptom control in children is provided.

viii. Referrals from level 1 and 2 service providers are received and managed with regards to pain and symptom management in the child. Referring back and ongoing support take place as required to ensure that the child receives good pain and symptom management regardless of the place of care.

ix. Training and mentorship in pain and symptom assessment and management in children are given to level 1 and 2 service providers.

References:

1. Frager G and Collins JJ (2006) Symptoms in life-threatening illness: overview and assessment. In: Goldman A, Hain R and Liben S (Eds) *Oxford Textbook of Palliative Care for Children*. Oxford University Press, Oxford.
2. Drake R and Hain R (2006) Pain-pharmacological management. In: Goldman A, Hain R and Liben S (Eds) *Oxford Textbook of Palliative Care for Children*. Oxford University Press, Oxford.
3. World Health Organisation (1997) *Cancer Pain Relief and Palliative Care in Children*. World Health Organisation. Geneva.
4. Watson M, Lucas C, Hoy A and Wells J. (2009) *Oxford Handbook of Palliative Care*. Oxford University Press, Oxford.

Standard 3.3: Psychosocial care for children

Every child requiring palliative care has access to culturally- and age-appropriate psychosocial care, i.e. psychological and social care.

Intent/Rationale

An honest and open approach should be the basis of all communication with the child and their family. The family is the unit of care for the provision of psychological and social support[1]. Parents are central to a child's wellbeing and where possible they, or a designated carer, should be present and involved in all aspects of the child's care, guided by the age and wishes of the child[2]. It is important that age-appropriate care is provided to the child: care given should try to meet the needs of the child's age, developmental stage, and communicative and cognitive abilities[3 4 5].

Criteria

Primary/Basic level (1)

i. The care provider undertakes a basic assessment of the child's and their family's psychosocial needs.

ii. Community support for the child and their family with regards to basic psychosocial needs is promoted and provided for at a basic level.

iii. Referral systems are in place to ensure that the child and their family's basic psychosocial needs are met through a network of available services.

Secondary/Intermediary level (2)

i. All of level 1 plus:

ii. A comprehensive assessment of the child and their family's psychosocial needs is undertaken, and a plan of action developed to support these needs.

iii. The identified psychosocial needs of the child are met in an age-appropriate manner, by a professional care provider trained in social care skills for children. Where such care providers do not exist, formal arrangements are made to enable access to such care.

iv. On behalf of the child and their family, the service facilitates appropriate contacts with other networks within the community, where available, to ensure that the child's needs are met.

Tertiary Level/Specialist level (3)

i. All of level 2 plus:

ii. A children's social care professional is part of the core clinical team and provide services to the child and their family to address complex psychosocial needs.

iii. Training and mentorship in the psychosocial needs of children and their families is provided to level 1 and 2 service providers, as appropriate.

iv. Information is available on existing community-based social support networks where the child and their family can access care beyond that of the specialist organisation.

v. There is a well-documented process for receiving and managing referrals from level 1 and 2 service providers and other organisations, in order to meet the psychosocial needs of the child and their family.

vi. The service provider undertakes a leadership role with regards to psychosocial care for children and their families, including documentation of best practice and research.

References:

1. Amery J, 2009; Introduction, in: *Children's Palliative Care in Africa*; Amery J; Oxford University Press, London. In print.
2. Lewis M and Prescott H (2006) The impact of life-limiting illness on the family, in: Goldman A, Hain R and Liben S (Eds) *Oxford Textbook of Palliative Care for Children*. Oxford University Press, Oxford.
3. EAPC (2007) IMPaCCT: standards for paediatric palliative care in Europe.
4. Down G and Simons J (2006) Communication. In: Goldman A, Hain R and Liben S (Eds) *Oxford Textbook of Palliative Care for Children*. Oxford University Press, Oxford.
5. Orloff SF, Quance K, Perszyk S, Flowers WJ and Veale Jr E (2004) Psychosocial and Spiritual Needs of the Child and Family. In: Carter BS and Levetown M (Eds) *Palliative Care for Infants, Children, and Adolescents: a Practical Handbook*. The John Hopkins University Press, Baltimore.

Standard 3.4: End-of-life care in children

The unique needs of the dying child and their family are considered, the child is made as comfortable as possible and their dignity preserved.

Intent/ Rationale

Care providers need to be experienced and skilled in recognising when the terminal phase of the child's illness has begun in order to facilitate appropriate care. The beliefs and values of the child and their family regarding death and dying need to be addressed and respected, and they should be assisted to prepare and plan for death by discussing expectations in order to reduce fear and encourage involvement[1 2]. Memory books or boxes are a useful tool for helping children prepare for their death. Where possible, both the child and the family members are given the opportunity to say goodbye and express their last feelings and wishes[3 4].

Criteria

Primary/ Basic level (1)

i. Basic support for the dying child and their family is provided within their home setting.

ii. Provision is made to enable the child and their family to participate in customary or religious end-of-life rituals that have meaning for them.

iii. Basic spiritual and social support is provided by the community to the child and their family.

iv. The child's primary care giver is supported in their role.

v. There is a close working relationship with level 2 and 3 service providers to ensure that the child dies in peace and dignity.

Secondary/ Intermediary level (2)

i. All of level 1 plus:

ii. Symptoms in the dying child are assessed and documented.

iii. Treatment and care is based on the wishes of the child and their family.

iv. The child and the family are given information about the signs and symptoms of approaching death in a manner appropriate to their individual needs and circumstances.

v. End-of-life issues and the anticipation of the death of the child are honestly discussed with the child and their family in a socially and culturally appropriate manner.

vi. Immediately following the death of the child and during the early bereavement phase, families and caregivers are given time and support to help with adjustment to the death of the child.

vii. There is a close working relationship with level 1 and 3 service providers to ensure that the child dies in peace and dignity.

Tertiary Level/ Specialist level (3)

i. All in level 2 plus:

ii. Specialist advice is available for care providers on managing challenging symptoms and situations when caring for a dying child.

iii. A close working relationship is maintained with level 1 and 2 service providers to ensure that the child dies in peace and dignity.

iv. There is a well-documented referral process for ensuring the continuity of care for the dying child, wherever they may be cared for, and support is given to level 1 and 2 service providers as needed.

v. Guidance and support are available to any care provider who needs advice about ethical dilemmas related to end-of-life care and decision making.

vi. Debriefing is available for caregivers who need support following the death of a child who they have been caring for[5].

vii. The service takes a lead on establishing good practice in care for the dying child and their family, and teaches others how to care for the dying child.

References:

1. Palliative Care Australia. (2005) *Standards for Providing Quality Palliative Care for all Australians*. PCA Australia.
2. Bluebond-Langer M and DeCicco A (2006) Children's views of death. In: Goldman A, Hain R and Liben S (Eds) *Oxford Textbook of Palliative Care for Children*. Oxford University Press, Oxford.
3. Nasaba R, Defilippi K, Marston JM and Musisi S (2006) Chapter 29: Psychosocial and Spiritual Care. In: Gwyther L, Merriman A, Mpanga Sebuyira L and Schietinger H. *A Clinical Guide to Supportive and Palliative Care for HIV and AIDS in Sub-Saharan Africa*. APCA, Uganda.
4. Amery J, 2009; Introduction; In *Children's Palliative Care in Africa*; Amery J; Oxford University Press, London. In print.
5. Watson M, Lucas C, Hoy A and Wells J. (2009) *Oxford Handbook of Palliative Care*. Oxford University Press, Oxford.

Standard 3.5: Bereavement Care for Children

Formal mechanisms are in place to ensure that children and their families have access to age-appropriate bereavement care, information and support services.

Intent/Rationale

Bereavement care for the child and their family should commence at diagnosis and continue through the disease process, through death and beyond1. Different cultures have different beliefs about death and dying, therefore bereavement support should be provided in a culturally appropriate manner2. Children who are dying need to have the chance to mourn for what they are losing. Siblings of children who are dying need the opportunity to mourn for their brother and sister3 4. Children who have lost a parent also need the opportunity to mourn, yet often their feelings go unrecognised and unsupported5.

Criteria

Primary/Basic level (1)

i. Information about loss and grief and the availability of bereavement support is made available to the child's family before and after the death of the child, and to children before and after the death of a parent.

ii. Information about completing bereavement tools, e.g. memory books or boxes, is provided to families prior to the death of a family member, and support given to use these.

iii. Basic assessment is undertaken on how well the family is coping with regards to the death of a child and referral made for more intense support as required.

iv. Basic assessment is undertaken on how well children are coping with regards to the death of a parent and referral made for more intense support as required.

Secondary/Intermediary level (2)

i. All of level 1 plus:

ii. Good referral and support systems are in place between level 1, 2 and 3 service providers so that emotional and bereavement support for children can be provided to those who need it.

Tertiary Level/Specialist level (3)

i. All of level 2 plus:

ii. Guidelines are developed and available for providing bereavement support to children and their families.

iii. Professional care providers trained in bereavement support for children are available to support those with complex bereavement needs and to support care providers from level 1 and 2 service providers.

iv. A healthcare professional trained in bereavement support for children co-ordinates the bereavement support programme for children.

v. Education about loss, grief and bereavement in children is provided for staff and volunteers of level 1, 2 and 3 service providers.

References:

1. EAPC (2007) IMPaCCT: *standards for paediatric palliative care in Europe*.
2. Davies B, Attig T and Towne M (2006) Bereavement. In: Goldman A, Hain R and Liben S (Eds) *Oxford Textbook of Palliative Care for Children*. Oxford University Press, Oxford.
3. Watson M, Lucas C, Hoy A and Wells J. (2009) *Oxford Handbook of Palliative Care*. Oxford University Press, Oxford.
4. Davies B, Worden W, Orloff SF, Gudmundsdottir, Toce S and Sumner L (2004) Bereavement. In: Carter BS and Levetown M (Eds) *Palliative Care for Infants, Children, and Adolescents: a Practical Handbook*. The John Hopkins University Press, Baltimore.
5. Marston JM, Defilippi K, Marcus C, Nasaba R and Nieuwmeyer SM. (2006) Chapter 30: Loss, Grief and Bereavement in Children. In Gwyther L, Merriman A, Mpanga Sebuyira I and Schietinger H. *A Clinical Guide to Supportive and Palliative Care for HIV and AIDS in Sub-Saharan Africa.* APCA, Uganda.

Standard 3.6: Ethical care, human rights and legal support for children

Palliative care for children should be provided in a way that upholds the ethical and legal rights of the child.

Intent/Rationale

Every child is unique, with his or her own needs, strengths, values and beliefs. Children should have equal access to palliative care, irrespective of the family's financial status or where they live. The International Children's Palliative Care Network (ICPCN) Charter sets out the international standard of support that is the right of all children living with life-threatening conditions and their families[1]. The best interests of the child should be the primary consideration in all decision making[2]. Every child has the right to receive adequate pain relief and symptom management, to be treated with dignity and respect, and to be afforded privacy[3 4].

Criteria

Primary/Basic level (1)

i. All care providers should know and understand the rights of the child and their family, along with their organisation's responsibilities as identified in laws, charters and regulations.

ii. Care providers should work collaboratively with the community served in order to effectively protect and advance the rights of the child.

iii. The rights of the child and their family are made known to them in a language and form that they can understand.

iv. When the child is unable to understand his or her rights, a mechanism is put in place to ensure that his or her carers are included in the process of protecting those rights.

v. The child and their family are enabled to participate in care decisions through the provision of basic information regarding the care and treatment proposed.

vi. Support is provided to the child and their family to protect their rights to participate in the care process.

vii. There is a process in place to identify and respect the values and beliefs of the child and their family.

viii. Information on alternative care services is provided when the service provider cannot provide the care or services needed.

Secondary/Intermediary level (2)

i. All of level 1 plus:

ii. When the child is below the age of consent, consent is provided by the family and, where possible, assent from the child.

iii. The name of the legal guardian is recorded in the patient care file.

Tertiary Level/Specialist level (3)

i. All of level 2 plus:

ii. The service provider has a clearly defined consent process described in policies and procedures which can be shared with level 1 and 2 service providers as appropriate.

iii. Advice is provided to level 1 and 2 service providers on the legal and ethical rights of the child and how these can be implemented in palliative care practice.

References

1. ICPCN (2008) The ICPCN Charter. http://icpcn.org.uk/
2. Watson M, Lucas C, Hoy A and Wells J. (2009) Oxford Handbook of Palliative Care. Oxford University Press, Oxford.
3. EAPC (2007) IMPaCCT: standards for paediatric palliative care in Europe
4. Larcher V (2006) Ethics. In: Goldman A, Hain R and Liben S (Eds) Oxford Textbook of Palliative Care for Children. Oxford University Press, Oxford.

Principle 4: Education and Training

Introduction to the principle:

Palliative care education is one of the four components or pillars of the WHO Public Health strategy for palliative care, which must be addressed for the effective integration or establishment of palliative care in society and to change the experience of patients and families[1]. The quality of life of at least 100 million people would have improved if today's knowledge of palliative care was accessible to everyone[1]. In order to scale up palliative care provision in Africa, there is a need to make palliative care knowledge accessible to all service providers, as well as educators. Palliative care education and training should be looked at as a continuum, which begins at undergraduate level, through to specialist training and into continuing education. It is critical for ensuring that there are appropriate knowledge, skills and attitudes for all service providers, including care providers, patients, families and the general public[2].

Training needs to be competency-based and should target the various levels of service delivery, from primary to specialist services. APCA has developed a competency framework (available at APCA) which can be used alongside these standards in order to ensure that care providers are trained to the appropriate competency for their level of skill and cadre. Education and training should aim not just at knowledge and skills but also at attitudes, beliefs and values[3]. Clinical placements are a fundamental education strategy in healthcare education[3]. It is important to develop a trusting environment in which it is easy to seek help or support or to talk through a health worker's own feelings and concerns[4]. There should be a clinical component as well as an element of ongoing mentorship and supervision[5]. In education, as in other areas of clinical practice, the early experiences are very important in sending messages of enthusiasm for the subject, of its excitement, its place in medicine as a whole, and its value to patients and the public. Palliative care needs such leaders if it is to continue to grow and develop as a speciality[4].

Standard 4.1: Training for professional care providers

All professional care providers receive initial and ongoing training in palliative care to enhance their care giving knowledge and skills.

Intent/Rationale

Professional care providers need to be equipped with the knowledge and skills required in order to be able to provide a high standard of palliative care to patients, their families and other care providers. Palliative care providers in Africa face many challenges, including the lack of education of those delivering the care[6]. Education is a priority, and training needs to be provided for professional care providers in all care settings. e.g. hospitals, clinics and the community. People thus trained can then train community care providers and the family[7]. Training needs to be delivered in a culturally sensitive manner that is accessible to different segments of the population[8]. Professional care providers also need to learn how to implement the principles of palliative care, to enable them to provide holistic palliative care to patients and families[4]. Organising training and education for professionals is an element of good structure and process of care[9]. The important thing is not that all healthcare workers specialise in palliative care, but that palliative care training is available at various academic levels to fit in with the varying needs and requirements of the different professions[10].

Criteria

Primary/Basic level (1)

v. Professional care providers have received introductory training in palliative care that prepares them at the appropriate competency level outlined in the APCA core competency framework.

vi. Professional care providers have had experience in an established palliative care service.

vii. The introductory palliative care training course was given within the local cultural context and the context of multi-disciplinary teaching and learning[11].

viii. Professional care providers have access to a professional with recognised palliative care training for support and supervision.

ix. Professional care providers have access to continuing professional development.

Secondary/Intermediary level (2)

i. All of level 1 plus:

ii. There are some professional care providers who have a palliative care qualification that enables them to practise with the required competency for this level.

iii. All professional care providers receive ongoing in-service training.

iv. The outcome of education and training is assessed, monitored and evaluated [3, 4].

Tertiary Level/Specialist level (3)

i. All of level 2 plus:

ii. There are a number of professional care providers qualified at a specialist level in accordance with the competencies as defined in the APCA core competency framework.

iii. Professional care providers are supporting the designing and delivery of palliative care education and training programmes for all levels of care.

iv. The organisation contributes towards the development of palliative care curricula.

v. Palliative care training is evaluated and linked to competencies and standards.

vi. There is collaboration with health teaching institutions as appropriate.

vii. Training is available for teachers and trainers of palliative care.

viii. Career structures for palliative care professionals are developed and recognised[3].

References:

1. Stjernsward, Foley and Ferris (2007). WHO Public Health Approach for Palliative Care. *Journal of Pain and Symptom Management*, Vol. 33 No. 5 May 2007
2. Hospice Casa Sperantei (2002). *National Standards in Palliative Care*, Romania.
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Standard 4.2: Training for community care providers

Community care providers are trained, supervised and aware of their role in providing quality palliative care services as valued team members.

Intent/Rationale

Community care providers form part of an inter-disciplinary team whose focus is on providing holistic care, and they are a key resource within the community. They should therefore be given adequate training, reimbursement, professional supervision and a proper job descriotion[1]. Following training, the supervision of volunteers is vital to ensure that they are giving appropriate care[2].

Community care providers need to be selected, oriented, trained, placed and supervised. Community care provider programmes allow people who volunteer the opportunity to give of themselves to others in their community[3]. Community care providers supplement professional care providers, thereby enhancing access to palliative care services. Their services help in filling the gaps due to inadequate staffing in most services.

Communities are the end-users of palliative care services and therefore need to be involved in service planning, design, delivery and evaluation, achieved through community education. Volunteers bring great added value to palliative care when selected and deployed appropriately, and provided with good training and support[4]. It is the responsibility of every service provider at each level of service delivery to ensure the standards relating to community care providers are met.

Criteria

Primary/Basic level (1)

i. Community care providers have received introductory training in palliative care that prepares them at the appropriate competency level outlined in the APCA core competency framework.

ii. Training is based on an assessment of community needs and on the community's cultural context.

iii. Selection of community care providers is undertaken from the communities being served and based on clear criteria, such as the ability to read and write, language skills and previous training in care provision, among others.

iv. As part of training, community care providers are exposed to existing systems of care delivery.

v. Community care providers are supervised by the professional care providers within their team.

vi. Supervisors of community care providers are given additional training in supervision[3].

vii. Community care providers have access to continuing education.

viii. Community care providers are trained to link up with other resources and services in the community.

ix. Community care providers are given basic training in palliative care, with a focus on the continuum of care to facilitate patient referrals to available services. Training also covers key areas such as companionship; alleviating suffering; socialisation and emotional support to both the patient and family; standing in and allowing family members time off; bereavement support follow-up and assisting with community projects, public relations and community awareness and access to services.

x. There is collaboration among community care providers within the area and understanding that they can refer patients and their families to any available appropriate service.

xi. There is collaboration among services working with community care providers to avoid duplication in training them.

xii. The training of community care providers includes the elaboration of their roles and expectations.

Secondary/Intermediary level (2)

i. All of level 1 plus:

ii. Community care providers are trained to meet competency needs for this level as elaborated in APCA's core competencies.

iii. Community care providers are selected from a variety of backgrounds. Most have experienced a loss in their own lives; all have a genuine interest in giving of themselves in helpful ways.

iv. The selection of community care providers considers professionals such as retired nurses, teachers, etc.

v. Community care provider skills are further built to enable them to be trainers of level 1 care providers and to sensitise their communities on palliative care.

vi. There is monthly supervision for community care providers.

vii. There are appropriate training resources and materials available.

viii. The training of community care providers clarifies their role, benefits, expectations and limitations.

Tertiary Level/Specialist level (3)

i. All of level 2 plus:

ii. Community care providers are trained to meet competency needs for this level.

iii. Community care providers support the designing and delivery of palliative care education and training programmes for levels 1 and 2.

iv. Community care providers are updated on any advances in palliative care provision and have up-to-date knowledge and skills.

v. Community care providers are given comprehensive palliative care training, which incorporates theoretical and practical approaches to care delivery.

vi. Community care providers are good leaders who have the advocacy ability to reach both higher cadres of health providers and needy clients in the community, so that holistic care is accessible and affordable at all levels in a given context.

vii. Community care providers have additional education through attending ongoing support and education meetings.

viii. Community care providers work closely with the clinical team and acquire further skills through this process.

ix. Community care providers are given knowledge and skills in all the diverse areas of palliative care so that they become members of an integrated healthcare team, providing home care, education and support to patients and their families in their communities.

x. There is advocacy for community care providers to gain recognition by the formal healthcare sector and for standardised training, career pathways and formal support[1].

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Standard 4.3: Continuous education in palliative care

Continuous professional development is made available to all care providers working in palliative care.

Intent/Rationale

Continuing professional development is concerned with personal growth and satisfaction with performance. It emphasises the need to keep up-to-date. There is a strong moral imperative for the clinician in palliative care to keep up-to-date and for those involved in the education of professionals to be aware of the range of methods of teaching and assessment now available[1].

Continuous professional development within palliative care is important in ensuring that care providers continue to develop their knowledge and skills, and improve and refresh their existing knowledge. Professional development needs are assessed at the different levels of service provision and take into account the environment in which people are working, e.g. available resources and development requirements. Ideally a personalised development plan addresses the unique needs of a particular professional, and through development programmes, performance is improved. Within palliative care, professional development acknowledges both the need to improve generic skills which may have been part of foundational training as well as focusing on specialised areas of development particular to the palliative care field. Professional palliative care development aims to ensure that patients receive the best care possible and that best practice models are developed and shared.

Criteria

Primary/Basic level (1)

i. Development needs are identified for all care providers.

ii. Organisational policy makes provision to address the professional development needs of its care providers.

iii. Resources are available to support professional educational development.

iv. Professional development activities are recorded by the organisation.

Secondary/Intermediary level (2)

i. All in level 1 plus:

ii. Service providers have a continuous professional development plan which includes relevant care providers being identified and, where appropriate, supported to undertake palliative care training.

Tertiary Level/Specialist level (3)

i. All of level 2 plus:

ii. Staff development needs are identified through performance appraisal and form a part of ongoing professional assessment.

iii. Service providers offer professional development opportunities in palliative care to the wider health community, including level 1 and level 2 facilities and educational institutions.

iv. Systems are in place to evaluate the system of continuous professional development within service providers.

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Standard 4.4: Competencies for different cadres

All care providers have the appropriate competencies for the level of service offered.

Intent/Rationale

A competency is a specified attribute that an individual is expected to possess in order to perform a task or set of tasks effectively in a specified field or context. Competencies are behavioural and are useful for describing the individual's quality in relation to the demands of the tasks that they are required to perform. They are therefore useful in ensuring that care providers are trained to the appropriate competency for their level of skill and cadre[1].

Criteria

Primary/Basic level (1)

i. All care providers, including volunteers, should demonstrate appropriate competencies in providing palliative care to patients and their families.
ii. Clear referral systems are in place when care provision is required above the level of competency of the level 1 care providers.

Secondary/Intermediary level (2)

i. All in level 1 plus:
ii. There is a multi-disciplinary team of care providers, each demonstrating appropriate competencies that complement each other in order to provide palliative care to the patient and family.
iii. Clear referral systems are in place when care provision is required above the level of competency of the level 2 care providers, or in a setting where they are not familiar.

Tertiary Level/Specialist level (3)

i. All in level 2 plus:
ii. At least one member of the multi-disciplinary team should be trained as a specialist in their profession, thus demonstrating specialist palliative care competencies.
iii. Where children are being cared for, it is important that there are care providers with specific competencies for caring for children.
iv. Clear referral systems are in place with level 1 and 2 service providers when care provision is required at a different level.
v. When referring to another service provider, the organisation is aware of the level of competency within that service provider.
vi. Training and mentorship in palliative care are provided to level 1 and 2 service providers, with an emphasis on enabling service providers to have the appropriate competencies to care effectively for the patient and family.

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Standard 4.5: Supervision and mentorship

There is supervision and mentorship for all those trained to deliver palliative care.

Intent/Rationale

Appropriate supervision and mentorship are vital elements of any palliative care training programme.[1] Setting up mentorship programmes requires both individuals and organisations to change, which often meets initial resistance. Necessary skills include patience, perseverance and the maturity to deal with criticism constructively[6]. Supervisors and mentors have a vital role in helping students learn and making them feel supported and encouraged. It is important for healthcare workers who are new in the field of palliative care to have the supervision and mentorship of someone experienced as they undertake clinical placements and set up services in their own clinical environment[1].

The real importance of education lies in the value it adds to the student[2]. Supervision and mentorship provide formal and informal opportunities for learners to receive feedback on performance and to know how they are progressing as a result of training. Role models are of particular importance[3] to learning in palliative care, and supervisors and mentors can take on this role. Effective mentorship can help to extend the principles of palliative care[4]. Mentorship is vital in a new field such as palliative care, where professional practice is evolving and there are few senior leaders to serve as role models[5].

Criteria

Primary/Basic level (1)

i. Care providers receive support and supervision from professional care providers following training in palliative care.

ii. Care providers have access to ongoing support, supervision and mentorship whenever required.

Secondary/Intermediary level (2)

i. All of level 1 plus:

ii. Care providers with a training role are coached on how to mentor others[5] and provide supervision so that they are knowledgeable, experienced and supportive, with trusting relationships with supervisees[7].

iii. Mentors are motivated and have the skills needed to assist others in a positive, culturally sensitive and constructive manner[6].

iv. Mentors have the experience and willingness to involve a wide range of networking partners in the mentorship process.

v. Supervision and mentorship are guided by the competencies defined for each level of training and service delivery.

vi. Standardised tools are used to assess the knowledge and attitudes of care providers.

vii. Supervision and mentorship roles are reflected in employee polices and job descriptions.

Tertiary Level/Specialist level (3)

i. All of level 2 plus:

ii. A supervision and mentorship plan is incorporated into any training.

iii. There are standard assessment and evaluation measures for clinical skills following training.

iv. Supervision and mentorship are included in training standards of the service provider and there is infrastructure to sustain supervision and mentorship programmes.

v. There is a mechanism through which senior and more experienced care providers share knowledge with other care providers.

vi. There is short-term mentorship for care providers in core areas such as pain and symptom management and bereavement support.

vii. There are clinical mentorship programmes which include a range of learning opportunities such as attending family conferences and inter-disciplinary team meetings, observing clinical rounds, case studies and one-on-one teaching[5].

viii. There are written protocols and pocket guides for care providers to use in day-to-day service provision[5].

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Principle 5.0: Research and Management of Information

Introduction to the principle:

Research in palliative care remains unprioritised in spite of its importance to the optimal development of clinical services. Most developments are not being driven by research findings. There is limited data on the most cost-effective model for palliative care service delivery, or even on which models are effective. Large areas of practice are based on clinical experience rather than high-quality evidence – even in core activities such as pain control[1]. There is an urgent need to establish a substantial evidence base, given palliative care's status as a cross-cutting area of healthcare, relevant to many other specialities and disciplines[2]. Despite a growth in palliative care services in poorer countries, there is still a lack of evidence to support calls for the integration of curative and palliative care[3]. To advocate effectively to clinicians, policy makers, funders and educators, there is a need to demonstrate the effectiveness of palliative care alongside treatments and to offer models of care that are locally appropriate and proven effective in terms of both costs and outcomes[3]. There is also need for strategic investment in palliative care researchers, facilities and infrastructure[1], as well as national strategies for palliative care research and close links between academics and clinicians[4].

Decisions affecting patient care should be taken in light of all valid, relevant information (e.g. research results on patients' preferences and resources). Assessments should be made of the information's accuracy and its applicability to the decision in question[2]. African palliative care experts recognise that clinical and health service audit and research is desperately needed in order to establish how best to deliver palliative care in resource-poor settings, and to establish an information base relevant to the developing world[5]. A priority is to establish a vision for research development[6]. It is also essential that care providers can carry out relatively simple research and audit[2].

Despite the need for an evidence base[7], the research that underpins palliative care service provision in Africa is inadequate[6]. The Declaration of Venice, produced by the European Association for Palliative Care and the International Association for Hospice and Palliative Care, aims to identify palliative care research priorities in developing countries according to the needs of specific patient populations, taking into account prevailing socioeconomic and cultural contexts; it also recommends the production of a research agenda for palliative care that contributes to the development of a global research strategy by each national or regional association[8]. Research, Monitoring and evaluation, data management and reporting are essential in any information management system.

Standard 5.1: Research

Service providers are committed to ongoing quality improvement of care, through research and audit of service models, components and quality.

Intent/Rationale

Research in palliative care is essential for maintaining standards, advancing knowledge, and improving practice and outcomes for patients, and in order to be confident that current practice is best practice[1]. Evidence-based practice requires the integration of clinical expertise with the best available evidence on patients' values and preferences. Through evidence, palliative care providers justify why palliative care matters alongside curative approaches, and can influence change in clinical practice, the allocation of funds, and medical and nursing school curricula. People deserve the right to care that is evaluated and effective. There is a need for technical support and resources to enable care to be evaluated and offer frameworks for quality improvement. Time and resources allocated to research improve future access and outcomes for patients and families. Research and audit enable the best use of available funds[3]. Clinical research, health services research and needs assessments[9] are essential alongside situational analysis[3].

The principal questions that face palliative care professionals are those of clinical effectiveness and acceptability, service efficiency and organisation, and meeting changing needs in the population. They are concerned with what palliative care practitioners do and how they do it[1]. The standards by which practice is measured are key to clinical audit[10].

Criteria

Primary/Basic level (1)

i. Service providers contribute to research through collaboration and networking with level 2 and 3 service providers and other partners, e.g. on data collection.

ii. Care providers have access to basic training in research.

Secondary/Intermediary level (2)

i. All of level 1 plus:

ii. Service providers initiate and conduct audit and research, independently or through collaborative partnerships[6].

iii. Audit and research cover key service areas, including organisational management, all aspects of holistic care provision, children's palliative care, education and training, and research and information management.

iv. The populations served are involved as appropriate in the audit and/or research undertaken.

v. Procedures are in place to ensure that audit and/or research results are incorporated effectively and thoroughly into service development and implementation.

vi. Procedures are in place to ensure that audit and/or research results are fed back to the population being served.

vii. Care providers are encouraged and supported to publish audit and/or research findings, and to disseminate these to local, regional and international audiences.

viii. Service providers have a database of audit and research tools used.

ix. The methods used to conduct audit and/or research are documented and accessible to care providers.

x. There is collaboration with level 3 service providers over audit, research and quality improvement.

xi. The goals of audit and research include improving existing research capacity[6] among service providers.Audit and research findings are used to inform clinical practice, health policy and decision-making in ministries of health[6] and other relevant bodies.

xii. Audit and research include the perspectives of the patient, their family and care providers, professional care providers and the local community.

xiii. Research is conducted in compliance with the existing guidance and legal requirements of national ethical research agencies, and any additional ethics bodies as required within the country.

Tertiary Level/Specialist level (3)

i. All of level 2 plus:

ii. Care providers are trained in research and evidence-based practice.

iii. Care providers have access to information and resources on research and evidence-based practice, e.g. free access to freely available online peer-reviewed palliative care and related journals (e.g. via the search engine HINARI).

iv. Dedicated personnel are in place to advance the service's research agenda.

v. Opportunities are created for care providers to acquire additional training in audit, research and evidence-based practice.

vi. Service providers have a research strategy in place.

vii. Collaboration is undertaken with other research organisations (African and non-African, clinical and academic) to advance the research agenda.

viii. Methodologically rigorous evaluation of service provision (e.g. patient-level outcome data, cost-benefit analysis, etc.) is undertaken.

ix. Research and audit findings are benchmarked with other comparable service providers as a means of developing best practice models.

x. Service delivery is based on evidence obtained through audit and research.

xi. Training and mentorship in research is made available for level 1 and level 2 care providers.

xii. Advocacy for the development of a research culture to underpin palliative care both nationally and regionally is undertaken.

xiii. Service providers advocate with policy makers for palliative care service delivery, using evidence from audit and research.

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Standard 5.2: Monitoring and Evaluation

Service providers are committed to providing the best possible quality of care, and undertake quality improvement programmes through effective monitoring and evaluation of organisational goals, objectives and activities.

Intent/Rationale

Monitoring and evaluation (M&E) is critical for ensuring that successful interventions become part of an integrated health service. M&E offers powerful tools to ensure that funders, policy-makers, implementers and researchers remain abreast of the impact, efficacy, efficiency and overall success of programmes[1]. M&E also allows managers to follow the progress of their activities; compare what was planned to what is actually occurring; and assess the cost-effectiveness of the service. This enables managers to make informed decisions when planning services and to use optimally both human and financial resources to benefit patients and their families. M&E tracks performance, measures results and reports the progress of service delivery[1]. As measures of efficiency and effectiveness, good systems of monitoring and evaluation can be powerful tools in advocating for expanded services[2]. M&E is important at all levels of palliative care and for all organisations, whether small or large[1]. M&E also ensures that there is an integrated reporting system that systematically provides useful information to inform stakeholders on progress, challenges, successes and lessons learnt[2].

Monitoring is defined as a systematic process of collecting and analysing information to track the *efficiency* of the organisation in achieving its goals. Monitoring provides regular feedback that helps an organisation track costs, personnel, implementation time, organisational development, and economic and financial results to compare what was planned to the ensuing actual events.

Evaluation is defined as a systematic process of collecting and analysing information to assess the *effectiveness* of the organisation in achieving its goals. Evaluation provides regular feedback that helps an organisation analyse the consequences, outcomes and results of its actions.

M&E should be integral to every palliative care programme. It should be well coordinated and integrated into the programme from the start[1]. The WHO recommends that M&E activities are proportional to a programme's resources, accounting for about 10 per cent of its budget[3]. The collection of essential and useful information and data is central to an effective M&E system.

Criteria

Primary/Basic level (1)

i. Data is collected on all domains of palliative care[4] (i.e. physical or clinical, psychological, social, cultural and spiritual), and in other core programme/service areas such as organisational management and training and education.

ii. The service provider is monitored and evaluated from the perspectives of the patient, their family and carers, professional care providers and the local community.

iii. There are clear programme goals and objectives for effective monitoring and evaluation[1].

iv. It is agreed with primary stakeholders how and what data will be collected and analysed, what it means, how the findings will be shared and what action will be taken[5].

v. Data collection needs are clearly defined, and care and service providers know what is expected of them.

vi. The frequency of data collection is agreed and documented (e.g. monthly, six-monthly, annually, etc.). M&E activities are ongoing, with some indicators being measured more frequently (e.g. number of patients seen monthly) than others (e.g. the impact of care on patients and their families)[1].

vii. Both quantitative data (numbers associated with programme elements) and qualitative data (how well elements of a programme are carried out) are collected to give a complete picture of programmes and activities[1].

viii. Relevant data collection methods (e.g. focus groups, key informant interviews, routine service data) and tools (e.g. questionnaires) are identified, used and documented[1] including quantitative and qualitative methods[6].

ix. Service providers liaise with level 2 and level 3 services to ensure quality and improve their M&E tools and data collection activities.

x. There is a system for collecting appropriate, useful data[2 7], analysing it, sharing findings with stakeholders and linking them to action[5].

xi. Lessons are documented and used to improve care provision[5].

xii. Key stakeholders, such as care providers and communities served, participate in the process of M&E, e.g. in planning and managing it [5].

xiii. The M&E function is clearly defined and covers questions such as who initiates and undertakes the process, and who learns or benefits from the findings[5].

xiv. There are clearly defined indicators to be monitored and evaluated[4], which reflect the most important aspects of the programme[2].

xv. There is some form of work plan which guides annual activity implementation.

xvi. Care providers are trained in the basic skills of data collection and analysi[57].

xvii. Procedures are in place to ensure M&E results are incorporated into service development planning[8] (e.g. planning meetings).

xviii. Procedures are in place to ensure M&E results are fed back to the community being served (e.g. sensitisation meetings).

xix. M&E is incorporated into all programme activities and conducted throughout a programme's lifespan[9].

xx. Basic information management systems are in place (e.g. using Excel software) that can help identify and catalogue service and programmatic development.

Secondary/Intermediary level (2)

i. All of level 1 plus:

ii. Data analysis procedures are well-documented.

iii. Data usage is well-defined and documented.

iv. Regular data collection is linked to national databases.

v. All stages of programme development and implementation are monitored and evaluated using a results-based Monitoring, Evaluation and Reporting framework (MER), i.e. covering input, output, outcome and impact levels[2].

vi. There is a work plan which specifies organisational or programme goals, objectives, activities, what is to be measured and how to measure it.

vii. Appropriate collaborative partners are identified who can support the implementation of the M&E agenda[2].

viii. Dedicated personnel are in place to advance the service's data collection and M&E agenda.

ix. Care providers are trained in M&E and data collection to acquire additional skills and ensure data quality.

x. The impact of care on patients and their families is measured and documented.

xi. There is an M&E strategy in place[2].

xii. There is an integrated system for regularly providing stakeholders with useful information on progress, challenges, successes and lessons learnt[2].

xiii. M&E and audit tools are developed for or adapted to the local situation[3].

Tertiary Level/Specialist level (3)

i. All of level 2 plus:

ii. Useful national and/or regional level data monitoring palliative care services is collected and documented.

iii. A documented process for collecting minimum data requirements and performance indicators is in place and used to collect a minimum data set to profile service provision[8].

iv. Data on monitoring performance against service bench marks, standards, performance indicators and other agreed items is collected[10].

v. An M&E framework for the service is in place, which supplements its strategic plan[7].

vi. The M&E plan has data collection tools, measurable indicators and protocols[11].

vii. Appropriate findings are benchmarked with other comparable service providers as a means of developing best practice models[6].

viii. Advocacy for the development of an M&E culture to underpin palliative care both nationally and regionally is undertaken.

ix. Training and mentorship in M&E is available for all care providers, as well as to level 1 and level 2 service providers.

References:

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12. Data Collection: http://en.wikipedia.org/wiki/Data_collection

Standard 5.3: Data Management

Data is well managed and used to realise ongoing quality improvement in achieving the organisation's vision, mission and goals.

Intent/Rationale

Organisations should collect and manage data in a way that provides useful information to inform organisational goals and decision-making. Data is primarily collected to find patterns, relationships and trends that can help an organisation grow and increase its effectiveness. A well-developed information database gives end-users a resource from which they can easily create relevant reports, conduct analyses and inform the decision-making process[1].

Data management is defined as the process of developing data planning, practices and procedures and executing these on a regular basis to support the vision, mission and goals of an organisation.

Criteria

Primary/Basic level (1)

i. There is a documented system for data management.

ii. Types and uses of data required by the organisation are identified and documented.

iii. Structures or categories of data are well-documented for ease of retrieval.

iv. Systems for data storage are identified and well-documented for ease of data retrieval.

v. There is data on all domains of palliative care (i.e. physical or clinical, psychological, social, cultural and spiritual), and on other core programme/service areas such as organisational management and training and education.

vi. Care providers have basic training in data management.

Secondary/Intermediary level (2)

i. All of level 1 plus:

ii. A person responsible for data management is in place.

iii. Formal policies and procedures for data management are in place.

iv. The process of data movement from one place to another is clearly documented.

v. Clear systems of data back-up and recovery are in place.

Tertiary Level/Specialist level (3)

i. All of level 2 plus:

ii. A data management department with more than one person is established.

iii. A database administration system for managing data is developed, supported by administrators with the ability and authority to undertake data recovery and integrity testing, and ensure data security, availability, performance, and development and testing support.

iv. Effective data warehousing or storage is in place so data can be accessed and used efficiently.

v. There is a clear process of mining or sifting national data to show trends, relationships and patterns.

vi. Data is always used to inform the organisation's decision-making.

vii. Systems are in place to test data validity to ensure its integrity.

viii. Effective data storage procedures are in place to ensure data security.

ix. Care providers have additional training in data management.

x. Training and mentorship in data management is made available for level 1 and level 2 service providers.

References:

1. What is Data Management? www.tech-faq.com/data-managment.shtml

Standard 5.4: Reporting

Information generated from palliative care activities is accurately reported to all stakeholders on a regular basis, using standardised mechanisms, to inform palliative care service developments.

Intent/Rationale

Reporting is an effective way of assessing whether the implemented activity produced the desired results. It is normally supported by a reporting plan which addresses all stakeholders (e.g. service providers, patients, caregivers, and community and development partners).

The purpose of this standard is to ensure that stakeholders at all levels receive reports that accurately reflect the true situation on the ground. Palliative care providers should be able to give accurate reports to patients and caregivers on available palliative care services, and to government and donors on the numbers of patients cared for at a given time. Inaccurate reports can result in misinformation, wrong decisions being made and the waste of valuable resources. Underlying these concepts is the systematic, timely and integrated reporting of operationally useful information at periodic intervals. The reporting aspect of the M&E process is pivotal in that it helps organisations inform themselves and others (e.g. partners, donors and other critical stakeholders) on the progress of a programme, as well as the challenges encountered, successes achieved and lessons learnt from implementing it.[1]

Criteria

Primary/Basic level (1)

i. Reporting is appropriate for patients and their families, care providers, the wider community, donors and other important stakeholders.

ii. Reports reflect all domains of palliative care (i.e. physical or clinical, psychological, social, cultural and spiritual), and other core programme/service areas such as organisational management and training and education.

iii. Reports are written in a language that is understandable to stakeholders using appropriate reporting mechanisms and technology.

iv. A designated person is identified and supported to write reports.

v. Regular accurate reports are available.

vi. Primary stakeholders are given reports in a timely manner with clear information about the relevance of palliative care activities and results.

vii. Reports include details on palliative care services available, referral centres, the availability of palliative care specialists in the area and how they can be reached, challenges related to palliative care provision and possible solutions.

viii. Where necessary, support in reporting is obtained from level 2 and level 3 service providers.

ix. Reporting formats are designed to ensure that stakeholders report in a standardised way.

x. Reporting captures programme results at all levels including inputs, outputs, outcomes, impacts[2].

xi. Reporting systems are in place by which this data can be reported to donors, including against agreed targets.

Secondary/Intermediary level (2)

i. All of level 1 plus:

ii. Reporting is coordinated by a designated person to ensure that stakeholders (primary, secondary and tertiary) receive reports in a timely manner. This person coordinates with various people to ensure reporting is carried out thoroughly.

iii. Formal structured reporting formats are used to ensure that the reporting needs of stakeholders at all levels are met.

iv. Reporting needs are identified and shared with the other levels.

Technical support (training) and resources (computers and reporting templates) are available to the primary level. Level 1 capacity to generate and disseminate reports to all stakeholders is enhanced.

Tertiary Level/Specialist level (3)

i. All of level 2 plus:

ii. Reporting is carried out according to reporting plans and memoranda of understanding agreed between the implementer, the funders and other stakeholders (e.g. the government).

iii. All information and generated reports are collated and key results reported to internal and external stakeholders.

iv. Reporting plans are drawn, with key timelines, audiences and tools and methods to be used. A designated person is assisted by a committee to implement the reporting plan.

v. A reporting committee is formed to oversee implementation of the reporting plan, check all reports and messages being sent out to stakeholders, and guide management in making necessary decisions.

vi. Data quality audits are undertaken[2].

References:

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Other sources use:

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2. Monitoring and reporting on the health sector's response to HIV and AIDS treatment, prevention, care and support 2009-2010. WHO/UNAIDS/UNICEF. www.who.int/hiv/universalaccess2010/hiv_me_framework_2009-10
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Definitions

Anticipatory grief: A grief reaction is that which occurs in anticipation of an impending loss.

Assessment: The comprehensive evaluation of a patient's needs (physical, psychological, social and spiritual) and clinical history. It includes an evaluation of how the illness is affecting the whole family and their care needs.

Audit: A method of reviewing clinical practice against agreed standards or guidelines of care to identify areas for improvement in quality of care. Audits provide a framework for looking at what you and your colleagues are doing in relation to clinical care, learning from it and changing practice.

Autonomy: The respect for autonomy recognises the right and ability of an individual to decide for him- or herself, based on his or her own values, beliefs and life span. The patient's decision should be informed and well-considered, reflecting his or her values.

Beneficence: requires prevention or removal of harm, while doing or promoting good. It implies that the care providers should do positive acts in maximising the benefits of treatment. Examples include: delivering effective and beneficial treatments for pain or other symptoms and providing sensitive support to patients and their families.

Bereavement: is the state of having suffered a loss and incorporates the period of adjustment in which the bereaved learns to live with the loss. It is the loss of something dear to a person or deprivation.

By the clock: When medications are given 'by the clock' it means that it is given on a regular basis e.g. every 4 hours thus ensuring that there is an adequate level of the medication in the blood stream to maintain a therapeutic effect e.g. with analgesics.

By the patient: When medications are given 'by the patient' it means that the health care professional takes into account any preferences etc of a patient for taking medication, and is aware of other medications that they might be taking thus ensuring that they are not contraindicated.

Care plan: marks the start of the patient's palliative care journey. It is developed between the care provider and the patient at the beginning of care (on admission to a care programme) and is updated at regular intervals thereafter. It provides guidance for the end of the journey as well. Continual use of the plan of care enhances communication among the patient, family, and healthcare providers, which in turn helps ensure quality of care. The plan of care allows patients to maintain a sense of control over their lives by expressing their preferences for palliative and end-of-life care in a written plan of care. It allows for establishment of patients personal goals of care and allows for assessment of patient and family support systems. A plan of care enables a care provider to assess, manage and measure outcome and provides a guide for meeting the expectations and needs prioritized by the patient and family.

Care provider: This is anyone who is involved in the care of the patient, whether they be professional care providers, community care providers or family members.

Cerebrospinal fluid (CSF) analysis: this is a laboratory test to examine a sample of the fluid surrounding the brain and spinal cord.

Child: According to the UN convention on the Rights of the Child “A Child means every human being below the age of eighteen years unless, under the law applicable to the child, majority is attained earlier” . The laws in each country should define when majority is attained before the age of eighteen and this may be due to marriage, or the birth of a child. In some countries when a child has a child they become an ‘emancipated child’ which means that although by age they are still a child, they are legally now seen as an adult. It is important to be aware of the laws of each country when defining a child.

Child Headed Household: A child headed household is one where the main carer and provider in the household is a child under 18. In the absence of an adult carer they take on the full responsibility of the household including financial and bringing up younger siblings.

Clinical Supervision: this is a formal process of professional support and learning which enables individual care providers to develop knowledge and skills, assume responsibility for their own practice and enhance patient protection and safety of care. Clinical supervision allows staff to continually improve their clinical practice, develop professional skills, maintain and safeguard standards of practice.

Cognitive-behavioural therapies (CBT): these are mental and behavioural techniques designed to modify specific emotional, behavioural and social problems and alleviate anxiety, depression and distress. The therapy targets what the patient does, thinks and feels.

Competency: A specified attribute that an individual is expected to possess in order to perform a task or set of tasks effectively in a specified field or context. It is useful for describing that individual’s quality in relation to the demands of the tasks that he or she is required to perform, including knowledge, attitudes and behaviours, and skills. A person who is said to have achieved a given competency needs to have demonstrated that he or she has acquired a particular skill and is able to practise it to an acceptably high standard.

Collaboration: The act of working jointly with other people or organisations, rather than independently and in isolation.

Community: a group of people or organisations linked by social ties and interaction, share common perspectives, values and engage in joint action in geographical locations or settings.

Community care provider: A community care provider is someone providing care for the patient and their family, with supervision from professional care providers, but who does not have a professional qualification recognised by the Ministry of Health, e.g. community health workers, community volunteers, lay care givers, nursing aides. They will, however, have had some training to prepare them for their role.

Complementary therapies: These are therapies used together with conventional or orthodox medicine but do not replace this medicine. They include a diverse range of treatments and practices, based on different philosophies and beliefs that are used for healing mind, body, emotions and spirit. Examples may include biochemical therapies like herbs, dietary supplements, flower essences, aromatherapy oils; biomechanical therapies like massage; lifestyle therapies like environment, diet, exercise and mind-body techniques such as meditation, relaxation and imagery; bioenergetic therapies like acupuncture, therapeutic touch etc

Continuous Professional Development: Study or education activities designed to upgrade knowledge and skills of practitioners. It includes a range of short-term and long-term training courses which foster the development of employment-related knowledge, skills and understanding.

Culture: refers to learned patterns of behaviour, beliefs and values shared by individuals in a particular social group. It provides people with both their identity and a framework for understanding experience. Culture brings together a group of people with similar ethnic background, language, religion, family values and life views.

Data collection: The process by which information is gathered using specified methods such as in research.

Distress: an unpleasant experience of an emotional, psychological, social, or spiritual nature that interferes with a person's ability to cope with treatment. It extends along a continuum, from common normal feelings of vulnerability, sadness and fear, to problems that are disabling, such as depression, anxiety, panic and feeling isolated or in a spiritual crisis.

Dyspnea: An uncomfortable sensation or awareness of breathing. Patients may describe the feeling as shortness of breath, inability to get enough air, or suffocation.

Education: This is a programme of instruction of a specified kind or level – it is an instructive or enlightening experience and should impact knowledge, skills and attitudes. It is concerned with task-based problems and always has a value base.

End-of-life: This is the period when it has become obvious that death is inevitable and imminent. The primary aim of any treatment at this stage is to improve the patient's quality of life as opposed to extending length of life or curing the illness.

Essential palliative care medicines list: This is a list of medicines deemed to be essential for the provision of palliative care. It offers guidance and is produced with the aim of the provision of the best possible care for those with advanced life-threatening illness, uninfluenced by financial and other benefits or political considerations. This guide to essential palliative care medicines covers the most important classes of drugs required for palliative care. It is not necessary that every country includes all the medication identified, but that medication from each category is included, e.g. non-opioid analgesics, opioid analgesics, non-steroid anti-inflammatory drugs (NSAIDs).

Ethics: A code of behaviour that is followed, especially by a particular group, profession or individual, e.g. medical ethics – it shows the moral fitness of a decision or a course of action. Medical ethics is the study and employment of moral principles, duties and rights in the broad fields of medical conduct, applications and research. Ethics signify a general pattern or 'way of life'; a set of rules of conduct or 'moral code'; and inquiry about ways of life and rules of conduct.

Evaluation: A systematic process of collecting and analysing information to assess the effectiveness of an organisation in achieving its goals. Evaluation provides regular feedback that helps an organisation analyse the consequences, outcomes and results of its actions and makes conclusions that may inform future programmes.

Evidence-based medicine/practice: An approach to clinical practice and decision making which incorporates careful consideration of current care related research and the provision of relevant non-biased and comprehensive research based information to patients and their families to support decision making. This approach uses the best evidence available through research findings and/or demonstrated as being effective through a critical examination of current and past practices.

Faces scale: A scale often used for measuring pain in children, comprising six cartoon faces becoming progressively sadder, with expressions ranging from a broad smile (representing 'no pain') to very sad and tearful (representing 'worst pain'). The healthcare provider asks the child to choose the face that best represents how they feel or how much they hurt, with the number assigned to that face recorded by staff.

Family: A group of people bound by biological and legal ties and/or significant other(s). This term is used loosely and includes blood relations (adults and children) and all those whom the patient considers significant e.g. partners and close friends involved in the process of care and support to the patient. This includes all members of a household under one roof.

Family care provider: A member of the family involved in giving care and support to the patient.

Family members: The loved ones, relatives or significant others of the patient.

Fiscal responsibility: Financial responsibility.

Fiduciary responsibility: Holding assets in trust for a beneficiary, or the legal duty to act in the best interests of the beneficiary.

Genogram/family tree: A simple diagram that illustrates the relationships among family members from one generation to the next. It shows the medical history of family members and is a very useful tool that promotes discussion at a family meeting or with an individual patient. It also serves as useful record in the clinical notes.

Governance: The way in which organisations distribute powers, rights and accountabilities. Governance is the set of policies, roles, responsibilities and processes that a governing body within an organisation uses to guide, direct and control its resources to accomplish organisational goals. Governance can help protect an organisation from security threats or non-compliance liability.

Grief: The normal, dynamic process that occurs in response to any type of loss. It includes physical, emotional, cognitive, spiritual and social responses to loss.

Holistic needs: holistic needs encompass the physical, psychological, social, spiritual and cultural needs of an individual, all of which should be taken into account when providing palliative care.

Human resource management (HRM): The strategic approach to the management of an organisation's most valued assets: the people working there who individually and collectively contribute to the achievement of its objectives.

Human rights: The rights and freedoms to which all humans are inherently entitled. Human rights are based on human dignity.

Impacts: Results relating to long-term change and effects sought.

In-service training: Education for employees to help them develop their skills in a specific discipline or occupation. It takes place after an individual begins work responsibilities.

Indicator: A unit of information measured over time so that change can be documented. It gives specific information providing evidence of the achievement (or not) of results and activities and provide a basis for policy formulation, discussion and planning. Indicators serve as tools to examine trends and highlight problems and they should be Specific, Measurable, Attainable, Realistic and Time-bound (SMART).

Inputs: These are financial, human, material, technological and information resources used for the development and implementation of an intervention or programme to produce outputs. Specific examples include staff time, materials, money, equipment, facilities, volunteer time etc.

Inter-disciplinary team: one where professionals consistently work closely together to deliver joint care for a patient. Team membership varies but is composed according to the identified expectations and needs of the target population. The team typically includes doctors, nurses, social workers, counselors, pharmacists, personal support workers and volunteers. Other disciplines may be part of this team. Members contribute from their particular expertise, and the team shares information, decisions and works inter-dependently. Teams meet on a regular basis to discuss patient care and develop a unified plan of management for each patient, and provide support for other members of the team.

Justice: Relates to fairness in the application of care. It implies that patients receive care to which they are entitled medically and legally. Justice can be translated into 'give to each equally' or 'to each according to need' or to 'each his due'. The principle of justice implies a consideration for a common good and societal factors as well as being just and fair.

Leadership: is a process by which a person influences others to accomplish an objective and directs the organization in a way that makes it more cohesive and coherent. Leaders carry out this process by applying their leadership attributes, such as beliefs, values, ethics, character, knowledge, and skills. Although positions such as a manager, supervisor, lead, etc. give the authority to accomplish certain tasks and objectives in the organization, this power does not make one a leader, it simply makes one the boss. Leadership differs in that it makes the followers want to achieve high goals.

Legal rights: Provisions in the law that provide a framework to guide certain decisions or practices by a legal entity. This framework is defined in terms of requirements that need to be fulfilled in order to avoid liability. They are the rights a person is entitled to based on the law, e.g. constitutional rights. These rights are based on local laws, customs or beliefs. Legal rights (like laws) affect every citizen, whether or not the existence of such rights is publicly known.

Life-threatening illness (terminal illness): One where the likelihood of potential fatal outcomes such as death is high unless the course of the disease is interrupted. This does not mean that the disease is immediately resulting into death as there is might be a chance of long term survival.

Management: is the act of getting people together to accomplish desired goals and objectives. It comprises planning, organizing, staffing, leading or directing, and controlling an organization (a group of one or more people or entities) and its resources or effort for the purpose of accomplishing a goal. It involves resourcing which encompasses the deployment and manipulation of human resources, financial resources, technological resources, and natural resources to accomplish set targets or goals.

Memory Book/Box: Books or boxes that contain important legal documents and significant items connected to an individual's life and family history, for their loved ones to have after their death, e.g. for children to have after a parent's death, or for siblings to have after a child's death. Documents may include the individual's birth certificate, family photographs, drawings, simple wills, family trees and other items for loved ones to open up and appreciate later.

Mentorship: When a person with experience guides a person less experienced, in order to increase their knowledge and competence. Mentorship goes far beyond sharing knowledge and offers nurture, empowerment, mutual sharing, and growth. Mentorship is often seen as more of a personal relationship between two people than a managerial role.

Monitoring: A systematic process of collecting and analysing information to track the *efficiency* of the organisation in achieving its goals. Monitoring provides regular feedback that helps an organisation track costs, personnel, implementation time, organisational development and economic and financial results, to compare what was planned to ensuing actual events.

Multi-disciplinary team: one where professionals of different disciplines each carry out their particular role to care for the patient, but work independently of one another. The team is composed according to a patient's needs. In multi-disciplinary teams, professional identities are clearly defined and team membership is secondary. Each practitioner has a clearly defined place in the overall care of the patient, contributing their expertise in relative isolation from one another. In many settings, this may be the practical limit of teamwork. With such a team there are no regular team meetings, patient care may become fragmented and conflicting information given to patients and families.

National Formulary: A list of medications recognised by the national ministry of health for use within a country.

Networking: An arrangement where a grouping of individuals, organisations and agencies organised on a non hierarchical basis around common issues or concerns, which are pursued pro-actively and systematically, based on commitment and trust.

Non-maleficence: The principle that 'one ought not to inflict harm deliberately'. Violation of this concept may include offering information in an insensitive way, providing inappropriate treatment of pain or other symptoms, continuing aggressive treatment not suitable to the patient's condition, providing unwanted sedation, or withholding or withdrawing treatment.

Non-pharmacological methods: Therapies not involving the use of medicines, e.g. massage.

Outcomes: Results relating to intermediate change and effects sought, leading to longer term impacts.

Outputs: Results relating to short-term or immediate change effects and results sought, leading to outcomes.

Pain: Pain is what the patient says hurts. It is an unpleasant sensory and emotional experience associated with actual or potential tissue damage. It is frequently inadequately treated, resulting in unnecessary suffering. People's experience of pain is affected by physical, emotional, social and spiritual factors: the 'total pain' experience of the individual is important.

Palliative Care: An approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. (WHO, 2002)

Palliative Care for children: Palliative care for children represents a special field, albeit closely related to adult palliative care. 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' (WHO; 1998a).

Patient: A person or individual living with a life-threatening illness and is in contact with the health system seeking attention for a health condition. The term 'patient' (as opposed to 'client') is used in recognition of the individual's potential vulnerability at any time during the illness.

Pharmacological methods: Therapies that involve the use of drugs within medicine.

Policy: A set of statements or commitments to pursue courses of action aimed at achieving the defined goals of public or private institutions.

Post-exposure prophylaxis (PEP): Short-term anti-retroviral treatment to reduce the likelihood of HIV infection after potential exposure, either occupationally or through sexual intercourse. Within the health sector, PEP should be provided as part of a comprehensive package of universal precautions that reduces staff exposure to infectious hazards at work.

Pre-service training: Training that takes place before a person begins a job or task, e.g. prior to becoming a qualified nurse.

Professional care provider: Someone providing care for the patient and their family, who has a professional qualification recognised by the ministry of health and other line ministries in that country, e.g. doctor, nurse, social worker, counsellor, clinical officer, physiotherapist, etc.

Psychiatric disorders: Disorders of the mind. These include anxiety disorders, mood disorders, cognitive disorders (such as delirium and dementia), substance abuse and personality disorders.

Psychosocial care: Care concerned with the psychological and emotional wellbeing of the patient, their family and carers – including issues of self-esteem, insight into adaptation to the illness and its consequences, communication, social function and relationships. Psychosocial care involves the spiritual beliefs, culture and values of those concerned, and the social factors that influence their experience. It includes the practical aspects of care, such as finance, housing and aids to daily living. It involves professional carers – who also require support.

Psychological: Related to or arising from the mind or the emotions (as opposed to physical in nature).

Psychotherapy: Interventions which facilitate psychological adjustment, with a goal of managing anxiety related to great uncertainty and anticipatory grief. Family members are incorporated into the work, as they play a pivotal role in sustaining and strengthening emotional resources. Critical losses around control, personal identity and interpersonal relationships are common themes throughout the therapeutic process.

Qualitative data: Reveals how well elements of a programme are being carried out. It can show changes in behaviour or attitude (e.g. how well palliative care is being provided in the community). It reflects actual experiences and feelings related to a programme.

Quality improvement: the actions undertaken throughout the organisation to increase the effectiveness and efficiency of activities and processes, in order to bring added benefits to both the organisation and its beneficiaries. It includes defining specific activities; setting standards and targets for activities; developing programme indicators; measuring current practice; analysing gaps; reviewing the programme; implementing changes and monitoring and evaluation.

Quantitative data: Numbers associated with programmes, focusing on what and how often different elements are being carried out (e.g. number of home visits, number of palliative care training sessions conducted).

Referral system: The process whereby the care of a patient is transferred from one professional to another, usually for specialist advice and/or treatment.

Religion: A religion is a shared framework of beliefs and rituals which give expression to spiritual concerns. It is also a social context in which spirituality is nurtured, the meaning of life explored and identity formed.

Research: Any process in which data is collected, processed and analysed in a systematic, rigorous manner, and used to improve the services offered. Research seeks new knowledge and what the 'ideal' might be, and may take the form of an audit.

Service providers: Organisations or programmes providing care.

Special populations: Disadvantaged or marginalised groups in the community; people who may have characteristics (medical, cultural, cognitive, racial, physical, or a combination) that set them apart from other individuals in terms of needs.

Spirituality: An existential construct that includes all the ways in which a person creates meaning and organises his or her sense of self around a personal set of beliefs, values and relationships. This is sometimes understood in terms of transcendence or inspiration. Involvement in a community of faith and practice may or may not be a part of an individual's spirituality. Spirituality is also defined as a capacity and tendency that is innate and unique to all people. The spiritual tendency moves the individual towards knowledge, love, meaning, peace, hope, transcendence, connectedness, compassion, wellbeing and wholeness. It includes the capacity for creativity, growth and the development of a value system.

Standard: The desired achievable level of performance against which actual performance can be measured (i.e. a standard explains the level of performance to be achieved). It is a level of excellence required or specified. It serves as a basis for comparison and is a statement of expectations; an expected level of performance or quality.

Standard Operating Procedure: A set of instructions with the force of a directive, covering those features of operations that lend themselves to a definite or standardised procedure without loss of effectiveness. Standard Operating Policies and Procedures can be effective catalysts for performance improvement. Every good-quality system is based on standard operating procedures (SOPs).

Suffering: the distress associated with events that threaten the intactness or wholeness of the person. The causes of suffering include pain and other physical symptoms, psychological, social, cultural and spiritual.

Supervision: A process whereby a supervisor oversees the work of a supervisee, with a purpose of developing the supervisee with an expected outcome of the highest quality of service to the patient. Supervision does not only serve educational purposes, but also carries the aim of ensuring that the service is up to standard, through its support and management functions.

Supervisor: An appropriately qualified and experienced healthcare worker or other professional trained to oversee practice to ensure that care providers receive relevant experience to develop competencies and achieve expected outcomes. The supervisor's role is a formal one and is normally included in an individual's managerial responsibilities.

Terminal illness: A terminal illness (sometimes called terminally ill) is an illness which will eventually cause death. It describes an active and malignant disease that cannot be cured or adequately treated and that is reasonably expected to result in the death of the patient. Active and progressive disease which cannot be cured. Curative treatment is no longer appropriate, but palliative care is.

Traditional healers: These are generally divided into two categories: those that serve the role of diviner-diagnostician (or diviner-mediums) and those who are healers (or herbalists). The diviner provides a diagnosis usually through spiritual means, while the herbalist then chooses and applies relevant remedies.

Traditional medicine: The WHO defines traditional medicine as including diverse health practices, approaches, knowledge and beliefs incorporating plant, animal and/or mineral based medicines, spiritual therapies, manual techniques and exercises applied singularly or in combination to maintain wellbeing, as well as to treat, diagnose or prevent illness.

Training: The process of bringing a person to an agreed standard of proficiency by practice and instruction. It implies the learning of specific knowledge, skills or attitudes to tackle a particular clinical problem.

WHO Analgesic Ladder: Guidelines issued by the WHO to help clinicians manage pain using a three-step process (ladder). While originally developed with cancer pain in mind, the analgesic ladder has successfully been used for the management of other palliative care-related pain, such as that experienced by people with HIV and AIDS.

Work plan: A tool for monitoring and evaluation which shows the steps used to implement a programme’s activities and assess progress towards achieving its goals and objectives.

Appendices

Most tools and guiding documents mentioned in the standards are available at APCA and can also be accessed through APCA's website www.apca.org.ug and are not necessarily included as appendices. You can contact APCA directly to access these. Only samples of patient holistic assessment tools are included in the appendices below:

Appendix 1 Universal precautions for infection control *(Adapted from the WHO)*

Core Infection prevention and control interventions for health-care facilities at a glance.		
Specific interventions	**Target groups**	**Equipment and supply needs**
Hand hygiene	All health care workers + Visitors Patients	clean running water soap (mounted preferable) sinks or basins Towels Alcohol –based solutions
Personal protective equipment	All health care workers +	Gloves Gowns
Isolation precautions	Nurses Physicians Nursing aids Other	Gloves Gowns Masks Eye protection
Aseptic technique	Nurses Physicians Laboratory technicians Dental surgeons	Antiseptics Sterile gloves Sterile devices and instruments Sterile barrier devices
Cleaning and disinfection	Nurses Nursing aids Housekeeping staff Laboratory staff	Cleaning fluids Cleaning equipment Disinfectant
Sterilization	Sterilization staff Nurses Laboratory technicians Dental surgeons	Autoclaves and steam sterilizers Test strips Chemicals
Waste management	Health-care workers Waste handlers Logisticians	Sharps boxes and other Collection containers Storage space and container for interim storage Final disposal options Personal protection equipment for waste handlers
Antibiotic use protocol	Physicians	Essential list of antibiotics
Immunization and exposure management	All health-care workers +	Hepatitis B vaccine and other appropriate vaccines

+ Include nursing staff, physicians, dental staff, laboratory staff, housekeeping staff, waste management staff and mortuary staff.

Appendix 2 Examples of a holistic assessment tools

2 (a) Holistic Assessment tool (Adults)

This can be adapted to your setting.

File No ....

Hospice Rustenburg Admission Form[1] *(used with permission from the Hospice Palliative Care Association of South Africa)*

Contact Date:	Source of Referral:	Discharge Date:
Assessment Date:	Date of Birth:	Date of Death:
Professional Nurse:	Place of Birth:	Place of Death:
Community Care Giver:	Clinic attending:	Hospital attending:

Full name of Patient: ....

Known as .... Age.............. Diagnosis............

Sex .... Home language .... ID No ....

Occupation..................... Race .... Address ....

Tel.No .... Postal Address.....................................

....

Code .... Marital status ....

Significant other name .... No........ Next of Kin.................

Tel.No .... Relationship .... Postal Address ....

....

Code .... Primary Care Giver at Home ....

Relationship to patient .... Contact No ....

Other Organisations Involved.................... Doctor ....

Tel. No.............................. Specialist...................................

Tel. No.............................. Medical Aid ....

No .... Pharmacy ....

Tel.No .... Fax.No .... Religion.................

Minister......................... Tel.No ....

Admission tick list for P/N's use.		
Hospice booklet given:	Patients Rights Pamphlet	Newsletter
Medical ref: Received:	Hospice after hours	
To follow:	Consent to Hospice care	

Medical Details

Date. . . . . Present diagnosis . . . .

Treatment Given. . . . . Current Medication . . . .

Previous medical & surgical History . . . .

Habits . . . . Smoker . . . . How many per day . . . .

Alcohol . . . . How much per day . . . .

Immune Deficient Patients

Date of diagnosis. . . . . Pre & post test counselling done? . . . .

CD 4 Count . . . . Viral load . . . .

Opportunistic infections/tumours . . . .

Has patient been investigated for pulmonary TB? . . . .

Is patient on Anti TB drugs? . . . . Present symptoms . . . .

Present medications . . . .

Prognosis:

Is the patient aware of his/her diagnosis and prognosis?. . . . .

Is the significant other aware of patient's diagnosis and prognosis?. . . . .

Is the family aware of patient's diagnosis and prognosis? . . . .

Comments . . . .

Cultural and Spiritual Assessment

Do you have any cultural beliefs that may influence your care? . . . .

How can we be respectful to these beliefs? . . . .

How can we assist you with your spiritual needs? . . . .

Nutritional Assessment

Diet	Full	Soft	Fluids	
Appetite	Good	Fair	Poor	
Change in weight	Gained	Lost	kg	
Mouth	Clean	Sores	Thrush	
Dysphagia	No problem	At times	Major problem	
Nausea	At times	All the time	With certain foods	No nausea
Vomiting	At time	All the time	With certain foods	No vomiting

Comments . . . .

Current food diet consists of . . . .

Date of commencement of nutritional support (eg Sejo TM.) ....

Activities of daily living assessment

Abbreviations: 1 = Independent, A = Assistance, D = Dependant

Activities of daily living	I,A or D	Comments
Bathing		
Dressing		
Toileting		
Mobility		
Continence		
Feeding		

General comments on assessment of physical, psychosocial, social, spiritual, cultural needs of patient ....

Social Economic Assessment

Tick list of socio economic status of patient:

Type of dwelling	Brick	Mud	Planks
	Block of flats	Granny Flat	Own property
	Rented	Retirement Village	Old age home
Water Access	Tap	Central point	
Electricity	Yes	No	
Toilet	Water	Pit	None
Who does the patient live with?			
	Spouse	Partner	Relative
	Friend	Lives on own	Care worker \
	Domestic		
Financial	Very difficult	Difficult	
	Very comfortable	Comfortable	No income
	How many grants?		
	How many people in the home		
Medical Aid	Yes	No	
Access to food	Buy	Garden	Food parcels
	Need for referral?.................................		
	Who to		

Details of undertaker

Burial / Cremation . . . .

Undertaker . . . .

Certifying Doctor . . . .

Family /Friends to be contacted . . . .

I . . . . (Patient's Name and Surname) confirm that the information given above is in accordance with my wishes.

. . . . (Patient to sign agreement) Date . . . .

Witness: . . . .

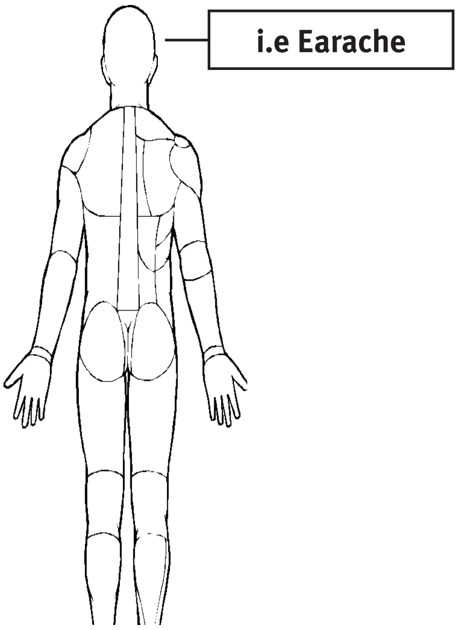
Pain Profile

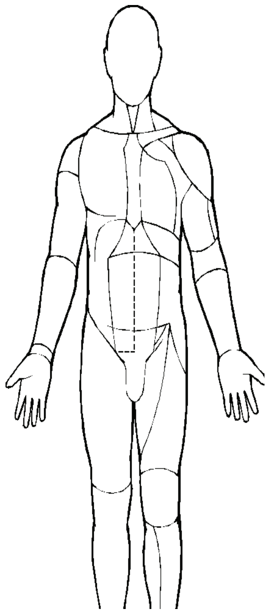
Pain Rating

Please mark pain level in appropriate place on scale

1________2________3________4________5________6________7________8________9________10

Please place an arrow to the location of the pain and specify area





Additional Comments

. . . .

Area	Area 1	Area 2	Area 3	Area 4
Frequency Intermittent, Constant				
Type Sharp, Dull, Colicky				
Intensity Mild, Moderate, Severe				
For Period Months, Weeks				

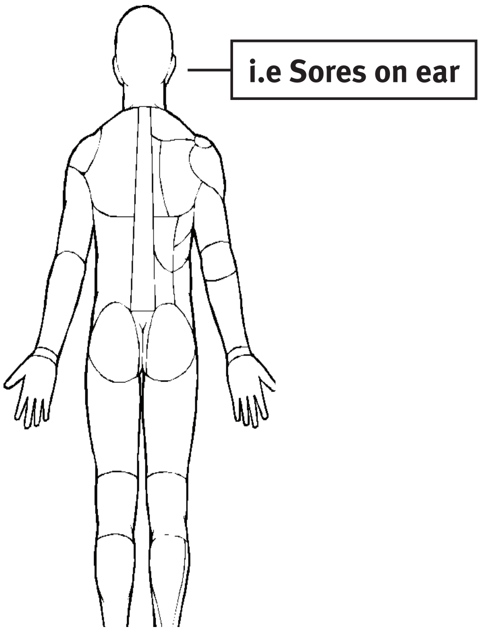
Additional Comments

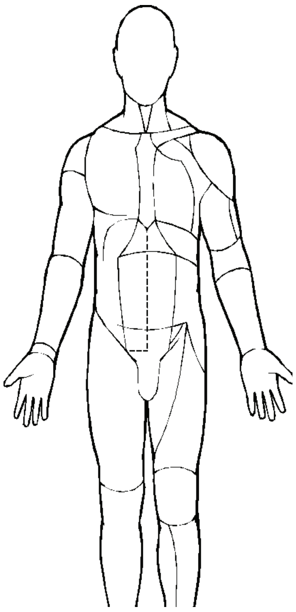
. . . .

Wounds and pressure sores.

Treatment

Please place an arrow to the location of any wounds and sores and specify area





Comments

. . . .

. . . .

Nursing Profile

Tick list for nursing care plan completed at first assessment.

Medical

Obtain better symptom control in following

☐ Pain
☐ Constipation
☐ Nausea / Vomiting
☐ Seizures
☐ Dysponea
☐ Prevention of bed sores
☐ Explanation of medicines

Nutrition

☐ Other ....

Services offered

☐ Home visits
☐ Bereavement care
☐ Memory work
☐ Nutritional support
☐ Counselling
☐ Support groups
☐ Assistance in accessing grants
☐ Other ....

Equipment given on loan

☐ Wheel chair	Sign	Date ....
☐ Commode	Sign	Date ....
☐ Egg box mattress	Sign	Date ....
☐ Hospital bed	Sign	Date ....
☐ o2 Concentrator	Sign	Date ....
☐ Bed pan / Urinal	Sign	Date ....
☐ Other	Sign	Date ....

Patient level of care

Category 1	Category 2	Category 3

Nursing Notes					
Date:		B.A.		Colour	
New complaints:		Urine		Oedema	
Pain		Mobility		BP	
Nausea/vomiting		Hygiene		Pulse rate	
Dysphagia		Mental State		Breathing	
Appetite/diet		Wounds/pressures		Other	
Current Medication:					
Other comments:					
Nursing care plan:					

Nursing Notes					
Date:		B.A.		Colour	
New complaints:		Urine		Oedema	
Pain		Mobility		BP	
Nausea/vomiting		Hygiene		Pulse rate	
Dysphagia		Mental State		Breathing	
Appetite/diet		Wounds/pressures		Other	
Current Medication:					
Other comments:					
Nursing care plan:					

Nursing Notes		
Date		Sign

Record of information / education given to patient and family/ caregiver.

Date	Information / education given by	Information/ education given to	Contents of information / education & comments

Physical Examination Date:. . . . . Sign: . . . .

Symptoms	Maj	Min	Abs	Comments
Abdomen				
Anaemia				
Anorexia				
Appetite				
Bleeding/discharge				
Catheter				
Cough				
Drowsiness				
Confusion				
Constipation				
Cyanosis				
Dehydration				
Diarrhoea				
Dysphagia				
Fits				
Headaches				
Haemorrhoids				
Incontinence				
Jaundice				
Lymphadenopathy				
Malgnancy				
Mental state				

Temp . . . . Pulse. . . . . Res . . . .

BP . . . . Weight . . . .

	Symptoms	Maj	Min	Abs	Comments
	Mobility				
	Mouth - dry				
	Nausea				
	Oedema				
	Pain				
	Pneumonia				
	Skin / rashes				
	Sleep				
	Sweating				
	TB				
	Thrush				
	Paralysis				
	Restlessness				
	Stoma				
	Vomiting				
	Weakness				
	Weight changes				
	Wounds/ sores				
	Other				

Planned frequency of visits: Weekly 2/52, 1/12/etc Emotional support only

Long intervals visits Telephonic support

State which. . . . . Sign . . . .

Date. . . . .

Nursing Care Plan

New complaints may include – pain, nausea / vomiting, Dysphagia, change in appetite/diet, BA, urine, mobility, hygiene, mental state, wounds/sores, colour, oedema, BP, pulse rate, breathing, etc.

Date	New Complaints	Treatment Plan	Follow up	Signed

Appendix 2 (b) Hospice master problem list and medications record chart

(Adapted with permission from Hospice Africa Uganda)

Problem List

Name. . . . . PC No . . . .

No.	PROBLEM[1]	Date Active	Date Inactive	Combined Problems (with dates)
1				
2				
3				
4				

[1] A problem is that which worries the health professional, patient or both. It includes diagnoses and other holistic problems. The No. stays with the problem throughout the follow up notes until inactive.

Appendix 2 (c) Medications record chart

(Adapted with permission from Hospice Africa Uganda)

NAME					IP No					
Drug Name	Dose	Reason for taking	On waking	10 AM	12 Noon	2PM	6 PM	10 PM	Bed time	DATE D/C

Appendix 2 (d) Holistic Assessment tool for children

(Used with permission from Mildmay Centre Uganda)

Initial nursing assessment (children) INA 1

Name:. . . . . **Reg. No.** . . . .

Age:. . . . . **Date of Birth:**. . . . . **Date of attendance:** . . . .

Caretaker's Name:. . . . . **Relationship:** . . . .

PRESENTING PROBLEMS: (AS PERCEIVED BY CHILD OR CARER)

1._. . . . . _

2.. . . . . _

TEMP:. . . . . **PULSE:** . . . . **BP:**. . . . .

RESP. RATE: . . . . **WEIGHT:** . . . . kg **HEIGHT:** . . . . cm

SYMPTOMS

Symptom Present?	Yes	No	Symptom Present?	Yes	No
Fatigue/Weakness	[ ]	[ ]	Weight Loss:	[ ]	[ ]
Night Sweats:	[ ]	[ ]	DIARRHOEA (3 Or More Loose Motions A Day):	[ ]	[ ]
Appetite Good?	[ ]	[ ]	Vomiting:	[ ]	[ ]
Nausea:	[ ]	[ ]	Headache:	[ ]	[ ]
Visual Problems:	[ ]	[ ]	Hearing Problems	[ ]	[ ]
Difficult Breathing:	[ ]	[ ]	Chest Pain:	[ ]	[ ]
Cough	[ ]None [ ]dry [ ]productive with blood [ ]productive but no blood				
MENTAL:	[ ]happy [ ]content [ ]anxious [ ]feels sad/depressed [ ]confused/disoriented				

PAIN ASSESSMENT:

State which pain: ______________________________: Grade the pain: |________|

0 - No pain

1 - Mild pain - does not interfere with ADL or sleep

2 - Moderate pain - interferes a little with ADL but not sleep

3 - Severe pain - interferes with ADL & sleep

4 - Worst ever pain

Describe the pain:

[ ]Dull [ ]Stabbing [ ]Burning [ ]Other______________
[ ]Constant [ ]Intermittent [ ]Regular [ ]Occasional [ ]Everyday
With what is it associated? [ ] Movement [ ] Eating
[ ] Night times [ ]Coughing [ ] Nothing

For Girls only:

Has started having menstruation: [ ] Yes , what age did she start? _______ [ ] no

BIRTH History

Was Born: [ ] At term [ ] Prematurely Birth Weight: ______kg

Breast feeding: [ ] ongoing [ ] BF stopped, state at what age:________ [ ] never breastfed

IMMUNISATION HISTORY

DPT: Complete Course? [ ] yes [ ] no
Polio: Complete Course? [ ] yes [ ] no
Measles: [ ] yes [ ] no
BCG: [ ]yes [ ]no
Others: ....

If parents are alive but status unknown, encourage them come for the test.

FAMILY

Mother: [ ] Well [ ] Sick [ ] Died
[ ]HIV +ve [ ]HIV -ve [ ]Not Known
Father: [ ]Well [ ]Sick [ ]Died
[ ]HIV +ve [ ]HV -ve [ ]Not Known

DEVELOPMENT

1. Has the child developed normally so far? Yes [ ] No [ ]
2. Is the carer concerned about the child's growth? Yes [ ] No [ ]

If yes, why?

In a school - age child:

3. Does the child go to school? Yes [ ] No. [ ] What class? [ ]
4. Are there any problems at school? Yes [ ] No. [ ]

If yes, please describe: ....

SOCIAL:

Number of people living in child's home? . . . .

Primary Carer's Name:. . . . .

Relationship to child: . . . .

4. Siblings: How many? Are they all well? [ ] Yes [ ] No
5. In what type of accommodation does family live?
   [ ] Own house [ ] With relatives [ ] Rented house [ ]Rented room
   [ ] Other: please specify:
6. Does the child look neglected? [ ] Yes [ ] No
7. Does the child have adequate access to food and water? [ ] Yes [ ] No
8. Family Financial situation: . . . .

9. Is the child disclosed to? [ ] Yes [ ] No
10. Does the carer have any other concerns/worries about the child?Yes [ ] No. [ ]

If yes, please describe: . . . .

PASTORAL & SPIRITUAL:

11. What is the child or family's religion?
    [ ] Anglican [ ] Roman Catholic [ ] Islam [ ] Other
12. Are the child's spiritual beliefs important to him/her?
    [ ] Yes [ ] No (go to next page) [ ] Unsure
13. 3. Would the child or the parent/carer like someone to pray with him/her?
    [ ] Yes [ ] No [ ] Not sure

14. Which spiritual leader would the child or parent/carer like to see?
    [ ] Roman Catholic Priest [ ] Chaplain [ ] Imam [ ] Own Spiritual Leader [ ] None

ANY OTHER COMMENTS?

. . . .

Assessed by . . . .

Medical assessment form (child) MAF 1 (To be made with reference to Nursing Assessment)

(Used with permission from the Mildmay Centre, Uganda)

Date:_____/______/________ **NAME:**. . . . .

Registration No: M . . . .

Sex: [ ] M [ ] F **Age:** .... **Date of Birth**: ....

A REASON FOR REFERRAL

....

....

B PRESENTING PROBLEMS

(see also Initial Nursing Assessment - INA)

....

....

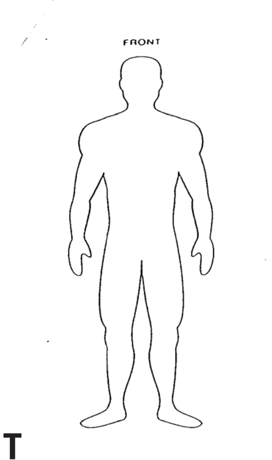
B1. CURRENT MEDICATION (indicate duration)

NURSING ASSESSMENT	**RECOMMENDATIONS**

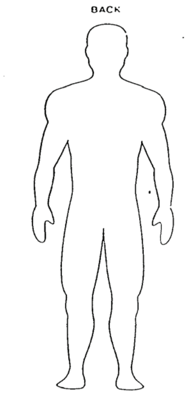
B2 HISTORY OF ALLERGIES:

[ ]None [ ] Allergic to Cotrimoxazole [ ] Other, specify

2.B3 PAIN ASSESSMENT



FRONT



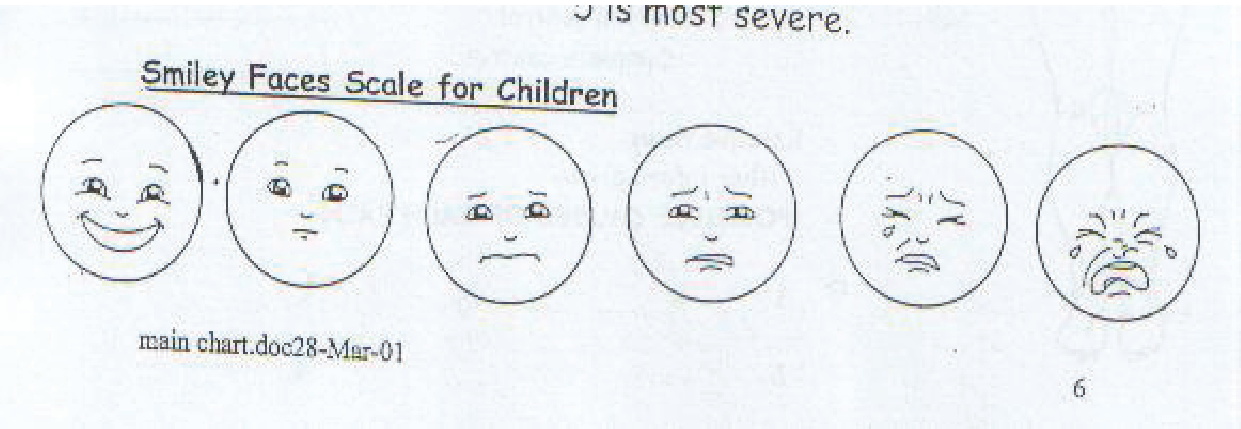
BACK

Show site of the pain and indicate intensity of pain on the diagram as per the scale below.

0 1 2 3 4 5 6 7 8 9 10

Code 0 = No pain Severe pain 5 = moderate pain 10 = worst ever/overwhelming pain

I do not have any pain 0 1 2 3 4 5 My pain could not be worse



WHO Clinical Staging

Clinical stage 1			
	PAST	**CURRENT**	**WHEN?**
Asymptomatic	[ ]	[ ]	
Persistent generalized lymphadenopathy	[ ]	[ ]	
Clinical stage 2			
Unexplained persistent hepatosplenomegaly	[ ]	[ ]	
Lineal gingival erythema	[ ]	[ ]	
Extensive wart virus infection	[ ]	[ ]	
Extensive molluscum contagiosum	[ ]	[ ]	
Unexplained persistent parotid enlargement	[ ]	[ ]	
Herpes zoster	[ ]	[ ]	
Angular cheilitis	[ ]	[ ]	
Recurrent oral ulceration	[ ]	[ ]	
Papular Pruritic Eruptions (PPE)	[ ]	[ ]	
Recurrent or chronic upper respiratory tract infections (otitis media, otorrhoea, sinusitis or tonsillitis)	[ ]	[ ]	
Fungal nail infections	[ ]	[ ]	
Clinical stage 3			
Unexplained moderate malnutrition or wasting not adequately responding to Standard therapy	[ ]	[ ]	
Unexplained persistent diarrhoea (14 days or more)	[ ]	[ ]	
Unexplained persistent fever (above 37.5°C intermittent or constant, for longer than one month)	[ ]	[ ]	
Persistent oral candidiasis (after first 6–8 weeks of life)	[ ]	[ ]	
Oral hairy leukoplakia	[ ]	[ ]	
Acute necrotizing ulcerative gingivitis or periodontitis	[ ]	[ ]	
Lymph node tuberculosis	[ ]	[ ]	
Pulmonary tuberculosis	[ ]	[ ]	

Severe recurrent bacterial pneumonia	[ ]	[ ]	
Symptomatic lymphoid interstitial pneumonitis	[ ]	[ ]	
Chronic HIV-associated lung disease including brochiectasis	[ ]	[ ]	

Unexplained anaemia (⇠8 g/dl), neutropaenia (⇠0.5 10_9 per litre) and or chronic thrombocytopaenia (⇠50 10_9 per litre)	[ ]	[ ]	
Clinical stage 4			
Unexplained severe wasting, stunting or severe malnutrition not responding to standard therapy [a]	[ ]	[ ]	
Pneumocystis pneumonia	[ ]	[ ]	
Recurrent severe bacterial infections (such as empyema, pyomyositis, bone or joint infection or meningitis but excluding pneumonia)	[ ]	[ ]	
Chronic herpes simplex infection (orolabial or cutaneous of more than one month's duration or visceral at any site)	[ ]	[ ]	
Oesophageal candidiasis (or candidiasis of trachea, bronchi or lungs)	[ ]	[ ]	
Extrapulmonary tuberculosis	[ ]	[ ]	
Kaposi sarcoma	[ ]	[ ]	
Cytomegalovirus infection: retinitis or cytomegalovirus infection affecting another organ, with onset at age older than one month	[ ]	[ ]	
Central nervous system toxoplasmosis (after one month of life)	[ ]	[ ]	
Extrapulmonary cryptococcosis (including meningitis)	[ ]	[ ]	
HIV encephalopathy	[ ]	[ ]	
Disseminated endemic mycosis (coccidiomycosis or histoplasmosis)	[ ]	[ ]	
Disseminated non-tuberculous mycobacterial infection	[ ]	[ ]	
Chronic cryptosporidiosis (with diarrhoed)	[ ]	[ ]	
Chronic isosporiasis	[ ]	[ ]	
Cerebral or B-cell non-Hodgkin lymphoma	[ ]	[ ]	
Progressive multifocal leukoencephalopathy	[ ]	[ ]	
Symptomatic HIV-associated nephropathy or HIV-associated cardiomyopathy	[ ]	[ ]	
a - Unexplained refers to where the condition is not explained by other causes.			

OTHER CONDITIONS:

	YES	NO	WHEN DIAGNOSED

CONDITION ON EXAMINATION

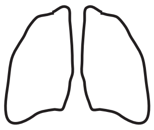
General Appearance: [ ] Looks well [ ] Looks ill [ ] Looks unkempt

[ ] Looks distressed [ ] Cachetic [ ] Dehydrated

Other comment:...

ON EXAMINATION (TICK YES OR NO)		YES	NO
Anaemia		[ ]	[ ]
Jaundice		[ ]	[ ]
Dependant oedema		[ ]	[ ]
Generalised Oedema (incl face)		[ ]	[ ]
Hair	normal	[ ]	[ ]
	Thin, discoloured	[ ]	[ ]
	Patches of tinea capitis	[ ]	[ ]

Ear	normal	[ ]	[ ]
	ear discharge(specify L or R)	[ ]	[ ]
	Otitis media	[ ]	[ ]
	Otitis externa	[ ]	[ ]
Nose	normal	[ ]	[ ]
	Ulcers	[ ]	[ ]
	Other: specify	[ ]	[ ]
Mouth	mouth and throat: normal	[ ]	[ ]
	Enlarged tonsils	[ ]	[ ]
	Ulcerated lips	[ ]	[ ]
	Candidiasis	[ ]	[ ]
	KS lesions	[ ]	[ ]
	Teeth: caries	[ ]	[ ]
	Gingivitis	[ ]	[ ]
Nails	normal	[ ]	[ ]
	Discoloured	[ ]	[ ]
	Fungal infection	[ ]	[ ]
	Clubbing		
Skin	normal	[ ]	[ ]
	Folliculitis	[ ]	[ ]
	Seborrhoeic dermatitis	[ ]	[ ]
	Tinea corporis/pedis	[ ]	[ ]
	Psoriasis	[ ]	[ ]
	Other	[ ]	[ ]

SYSTEM	Normal		If abnormal give details
	Yes	No	
	[ ]	[ ]	
Abdomen	[ ]	[ ]	
Cardiovascular	[ ]	[ ]	
Neurological	[ ]	[ ]	
Reproductive	[ ]	[ ]	
Other	[ ]	[ ]	

Weight:_______ Percentile for Weight _________

Height: _______ Percentile for height __________

SUMMARY AND CARE PLAN

Investigations ordered	State any available results on this first visit
[ ]FBC	
[ ]CD4	
[ ]LFTs	
[ ]RFTs	
[ ]VDRL	
[ ]Crag	
[ ]sputum	
[ ]Pregnancy test	
[ ]B/S	
[ ]X-Ray	
[ ]Urinalysis	
Other ______________________________	

F.1 Presenting Symptoms/problems with severity score

Symptom/Problem	Severity Score
1.	

FUNCTION: [ ]Work [ ] Ambulatory [ ]Bedridden

WHO STAGE: |________|

F 2. DIAGNOSIS AND TREATMENT WITH CARE PLAN

DIAGNOSIS (or symptom for treatment)	TREATMENT
1.	
PROPHYLAXIS	

CARE PLAN:Refer to

[ ] External Specialist Name: . . . .

[ ] Hospital for admission Name of Unit: . . . .

[ ] Physiotherapy

[ ] Counselling

[ ] OT/Stress Management

[ ] Nutritional advise

[ ] Pastoral Care

Next Appointment: _____/_____/___________ Today's date______/_______/________

Signature of examining clinician:. . . . .

Appendix 3 APCA African Palliative Care Outcome Scale (African Palliative Care Association)

The African Palliative Care Association (APCA) is currently in the process of developing comprehensive user guidelines to assist with the correct and consistent use of the APCA African Palliative Outcome Scale (POS). These will be available at the APCA website www.apca.org.ug

PATIENT NO. _____	POSSIBLE RESPONSES	Visit 1 DATE _____	Visit 2 DATE _____	Visit 3 DATE _____	Visit 4 DATE _____
ASK THE PATIENT					
Q1. Please rate your pain (from 0 = no pain to 5 = worst/overwhelming pain) during the last 3 days	0 (no pain) - 5 (worst/overwhelming pain)				
Q2. Have any other symptoms (e.g. nausea, coughing or constipation) been affecting how you feel in the last 3 days?	0 (not at all) - 5 (overwhelmingly)				
Q3. Have you been feeling worried about your illness in the past 3 days?	0 (not at all) - 5 (overwhelming worry)				
Q4. Over the past 3 days, have you been able to share how you are feeling with your family or friends?	0 (not at all) - 5 (yes, I've talked freely)				
Q5. Over the past 3 days have you felt that life was worthwhile?	0 (no, not at all) - 5 (Yes, all the time)				
Q6. Over the past 3 days, have you felt at peace?	0 (no, not at all) - 5 (Yes, all the time)				
Q7 Have you had enough help and advice for your family to plan for the future?	0 (not at all) - 5 (as much as wanted)				
ASK THE FAMILY CARER					
Q8. How much information have you and your family been given?	0 (none) - 5 (as much as wanted) N/A				
Q9. How confident does the family feel caring for ____?	0 (not at all) - 5 (very confident) N/A				
Q10. Has the family been feeling worried about the patient over the last 3 days?	0 (not at all) - 5 (severe worry) N/A				

Appendix 4 Family relationships assessment tools

(a) A guide or checklist for conducting family meetings

(Used with permission from the memorial Sloan-Kettering Cancer Centre {MSKCC})

Checklist for family meeting in palliative care

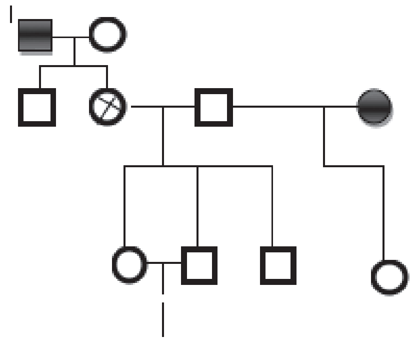
1. Round of introduction and welcome.
2. State goal of meeting together.
    a) To review where the patient's illness is at;
    b) To consider the family's needs in providing care;
    c) To conduct routine Family Relationships Index (FRI) screen about how the family functions as a group;
    d) To aim at optimizing the journey ahead.
3. Check for any other agendas the family might have.
4. Clarify the family's understanding of the seriousness of illness.
5. Clarify the family's understanding of the current goals of medical care.
6. Clarify the family's view of what the future holds:
    a) Has the place of death been discussed?
    b) If at home, who from the family will be providing care?
    c) If in a hospital, who will accompany? help? Support?
7. Are there key symptoms that are a concern to the family?
    a) Any medication or treatment concerns?
    b) Any hygiene issues?
    c) Any concerns about walking, moving, transferring?
    d) Any concerns about nursing or hospice visits?
    e) Any concerns about accessing palliative care resources?
    f) Any needs for respite?
8. FRI screening: "we are interested in how families cope and manage. We have a questionnaire that will help us understand your family. Would any family members who haven't yet completed our family questionnaire please do so? Thank you"
9. Clarify how family members are managing emotionally? Is anyone a concern or do you expect family members to manage ok? Is there anything we can do to help?
10. Affirm family's commitment, willingness, caring concern, for each other-something that is genuinely positive about the family style.

11. “we have a booklet that is intended as a resource or guide to help families in their care giving role. It doesn’t have to be read all at once, but can be referred to in the time ahead on an ‘as needed’ basis. Many families have found it helpful to for a number of family members to read it through. A number of patients have also said it was helpful.”
12. Before concluding, are there any questions that you have as a family?

Appendix 4 (b) The family tree

(Source: Kaye P; Symptom Control in Hospice and Palliative Care; 2006;134-135)

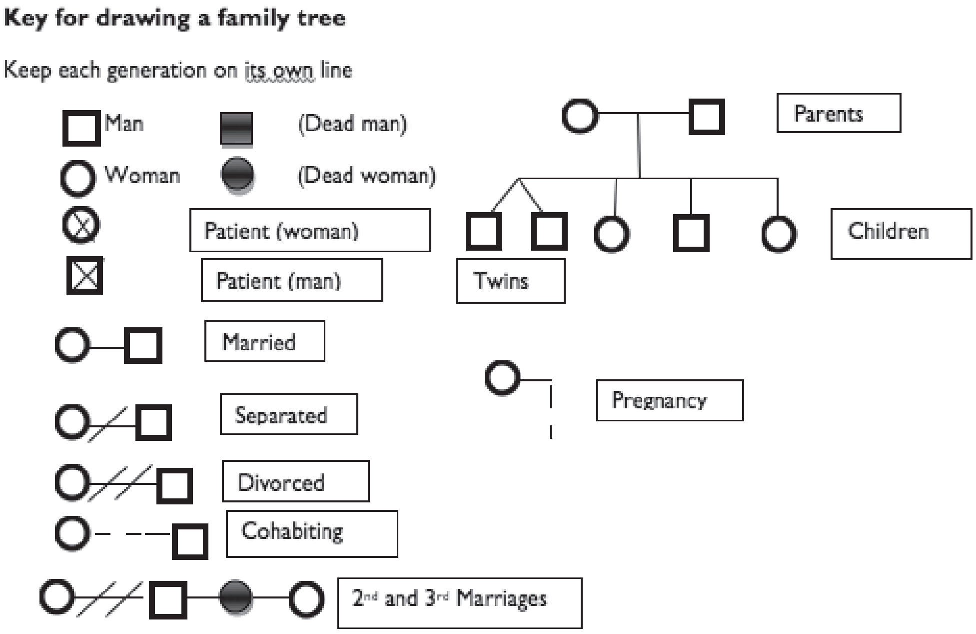
This can be included in the holistic assessment tool.



- Father died of cancer
- Mother is frail
- Husband's first wife died of cancer
- First grandchild expected in four months
- Step daughter is estranged.

Key for drawing a family tree

Keep each generation on its own line



Appendix 5 Distress Thermometer

(Used with permission from the National Comprehensive Cancer Network through Memorial Sloan-Kettering Cancer Center)

The distress thermometer (DT) is a rating scale used to measure distress: 0 (no distress) to 10 (extreme distress) - it is similar to the rating scale used to measure pain. It serves as a rough initial single item question screen, which identifies distress coming from any source even if unrelated to cancer. The 35 item Problem List, which is on the page with the DT, asks patients to identify their problems in five different categories: practical, family, emotional, spiritual/religious and physical.

The patient in the waiting room places a mark on the DT scale answering: How distressed have you been during the past week on a scale of 0 to 10? Scores of four or higher suggest a level of distress that has clinical significance. If the patient's distress level is four or higher, the palliative care team member looks at the problem list to identify key issues of concern and asks further questions to determine to which resource the patient should be referred. If the patient's distress level is mild (score is less than 4 on the DT), the primary team may choose to manage the concerns by usual clinical supportive care management. DT has been validated by several studies in patients with different types of cancer and has shown good sensitivity and specificity.

How to use the distress thermometer

Stage one:

1. Explain what you are doing and ask the patient if they are willing to go ahead with what you are proposing. For example: *You are mid-way through your radiotherapy treatment so I'd like to spend a few minutes with you to see how you are managing. We' ve got a lot of areas to cover, and we only have ….minutes, so this assessment has been structured in a particular way. It is up to you how much you wish to tell me but of course if you have concerns we won' t be able to help you with them if we don' t know what they are.*
2. Ask the patient to look at the Distress Thermometer (see attached).
    a) Ask them to rate globally their distress over the past week
    b) Then ask them to tick any items that have been of concern to them over the past week
3. Ask the patient to consider which is the most important concern that is contributing to their overall distress. Note that it may not appear on the list and would therefore need to be written on the form.
4. Record this ranking (i.e. 1st) on the assessment sheet directly beside the tickbox.
5. Then ask for the next most highly ranked concern and ask the patient to rate this.
6. Rank order and rate the top 4 concerns rather than all of them (though all concerns that are relevant should be check-marked on the sheet).

Stage two:

1. Turn the page over. Ask the patient to consider the highest-rated concern again. Ask them to use the thermometer again to rate the individual item as to the level of distress this has caused them over the past week. Then go into it in a little more depth; what does it involve? When did it start, what does the patient think it means, what may be maintaining it?

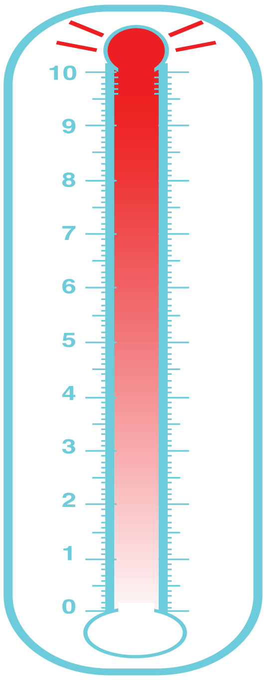
Problem-solving

1. What is the nature of the problem or concern facing you?
2. Brain-storm a list of possible options without limiting yourself to 'sensible' or logical options
3. Describe the pros and cons of each option by imagining its consequences
4. Decide upon the best solution, all considered
5. Describe the steps needed to implement this plan
6. Implement the plan if possible within an agreed timeframe
7. Evaluate how well the outcome solved the problem and return to the brain-stormed list to consider further options if needed

1. Consider with the patient what might be done to resolve it. Model a problem-solving approach towards resolving the problem (*see box*) and think about taking one of the following actions:

- Some concerns may be resolved immediately (e.g. providing further information, prescribing an analgesic) or through a further consultation with a professional at a later date.
    - Some concerns may be resolved through the patient taking action (becoming more socially active again, obtaining further information, attending a support group, taking more physical activity etc.)
    - Some concerns may require a referral to another service (other medical specialist, social worker, spiritual leader, clinical psychologist, counsellor etc). It is essential that the professional conducting the interview is aware of specialist resources that are locally available as well as their referral criteria. In discussing a possible referral to a 'mental health professional', such as a psychologist or psychiatrist, it is important to reassure the patient that such referrals are commonplace and in no sense a sign of failure, shame or mental illness.

2. Summarise what you have discussed and what steps, if any, *you* will take (e.g. referral) and those that the patient has agreed to take. Thank the patient and tell them that the summary sheet will be placed in their case notes. Allow the patient to see the sheet again if they wish (and provide them with a copy of it where possible). Finally, ask the patient if they have any remaining questions.



Extreme distress

No Distress

RANKING

Practical Problems

[ ] Child care
[ ] Housing
[ ] Finances
[ ] Transportation
[ ] Work/school

Family Problems

[ ] Dealing with children
[ ] Dealing with partner

Emotional Problems

[ ] Depression
[ ] Fears
[ ] Nervousness
[ ] Sadness
[ ] Worry
[ ] Anger
[ ] Unable to make plans

Spiritual/religious concerns

[ ] Loss of faith
[ ] Relating to God
[ ] Loss of meaning or purpose of life

RANKING

Physical Problems

[ ] Appearance
[ ] Bathing/dressing
[ ] Breathing
[ ] Changes in urination
[ ] Constipation
[ ] Diarrhoea
[ ] Eating
[ ] Fatigue / Tiredness
[ ] Feeling swollen
[ ] Fevers
[ ] Getting around
[ ] Indigestion
[ ] Mouth sores
[ ] Nausea
[ ] Nose dry/congested
[ ] Pain
[ ] Sexual
[ ] Skin dry/itchy
[ ] Sleep
[ ] Tingling in hands/feet
[ ] Metallic taste in mouth

Other Problems ....

Highest Ranked Concern	**RATING**	**Description of History of Problem**	**Plan of Action**

Appendix 6 FICA Questions for spiritual assessment

The FICA method of taking a spiritual history

F	Faith and belief. Ask: Are there spiritual beliefs that help you cope with stress or difficult times? What gives your life meaning?
I	Importance and influence. Ask: Is spirituality important in your life? What influence does it have on how you take care of yourself? Are there any particular decisions regarding your health that might be affected by these beliefs?
C	Community. Ask: Are you part of a spiritual or religious community?
A	Address/action. Think about what you as the health care provider need to do with the information the patient shared—e.g., refer to a chaplain, meditation or yoga classes, or another spiritual resource. It helps to talk with the chaplain in your hospital to familiarize your-self with available resources.

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