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Guide to Pain Management in Low-Resource Settings

Chapter 8
Principles of Palliative Care

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What is palliative care?

Palliative care is 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. This widely accepted definition of the World Health Organization from 2002 includes some changes compared to an older WHO definition from 1990. The definition explains and reinforces the holistic approach, which not only covers the physical symptoms, but extends to other dimensions and aims of care for patients as they suffers now with their disease, with their own personal story, and in their actual setting and social context.

The WHO provides a similar definition for palliative care for children—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 children's 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 centers, and wherever children call home.

What are the principles of palliative care?

Palliative care is a philosophy of care that is applicable from diagnosis (or beforehand as appropriate) until death and then into bereavement care for the family. Often palliative care is seen as focusing on end-of-life care only, and while this is an important aspect of palliative care, it is only one component of the continuum of care that should be provided. It is focused on the needs of the patient, their families and carers. It is the provision of comprehensive holistic care with the patient at the center of that care, and is dependent on attitudes, expertise, and understanding. It is a philosophy that can be applied anywhere—across a range of skills, settings, and diseases. The WHO has outlined several principles that underpin the provision of palliative care, including statements that 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;

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- Uses a team approach to address the needs of patients and their families, including bereavement counseling 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, radiation, or antiretroviral therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

How is palliative care provided?

Palliative care can be provided across a range of care settings and models, including home-based care, facility-based care, inpatient and day care. Care can be provided in specialist as well as general settings and should, where possible, be integrated into existing health structures. The concept of palliative care should be adapted to reflect local traditions, beliefs, and cultures—all of which vary from community to community and from country to country.

Palliative care is holistic and comprehensive, and thus ideally it should be delivered by a multidisciplinary team of care givers, working closely together and defining treatment goals and care plans together with the patient and his or her family. In many resource-poor countries the multidisciplinary care team will include community workers and traditional healers as well as nurses, doctors, and other health care professionals. Nurses have a key role in the provision of palliative care due to their availability within resource-poor settings, and they are often the coordinators of the multidisciplinary team. The health care professional may be working alone with little support from others, particularly in rural settings. Community health workers and volunteers can provide support to the health workers and have been trained with good effect to support them with basic medical care. In many resource-limited settings, community workers and volunteers are indispensable for the provision of palliative care and in particular with regard to social support for patients.

There are however, specific situations where professional support from peers or from a team is required. Ethical decision-making in complex situations, disagreeable patients or families, or family systems with complex conflicts may trigger a need for such support. For health care professionals working on their own it is very helpful to identify peers or a support team on which they can fall back if needed, to discuss problems, share responsibility, or get emotional support. This support will enable them to continue in their work for the benefit of the patients.

Case report

Grace is a 43-year-old widow. Her husband died from an "unknown cause" 4 years ago, and she has been bringing up her two children, who are aged 12 and 14, on her own since then. One year ago she noticed that she was getting pain on micturition and that her periods had become irregular and that she was bleeding mid-cycle. She did not seek medical help initially as she thought that this was just part of getting older, and culturally it was not appropriate to discuss such problems with anyone. Six months later, having been to visit a traditional healer first, and not responding to their treatment, she eventually visited her local health center as the pain was getting very bad; she was experiencing bleeding and found that she was unable to keep herself clean and free from odor. On examination at the local health center she was referred to the district hospital, from where she was referred to the national cancer center, where she was diagnosed as having a fungating cervical tumor. Initial diagnosis was of a Stage IV cervical carcinoma, which had spread to her lymph nodes, her pelvis, and her liver. Treatment with surgery was no longer an option, and chemotherapy was not available, so five fractions of palliative radiotherapy was given to try and reduce the pain and the bleeding. She had lost weight over the past 6 months and was suffering from fatigue. While she was an inpatient in the cancer unit she was seen by the local palliative care team because of severe pain in the pelvis and lower back. Pain management included low-fraction radiotherapy and she was commenced on 5 mg oral morphine every 4 hours. This dose was increased gradually to 35 mg of oral morphine every 4 hours with a prescribed rescue dose as required. This regime was combined with 12.5 mg amitryptiline at night for neuropathic pain, and it resulted in significant pain relief. She was also prescribed an antiemetic for nausea and a laxative to prevent her from becoming constipated from the morphine, and to soften her stool to reduce discomfort from the fungating wound on defecation. With the radiotherapy along with a cleansing regimen as well as use of topical metronidazole, the odor disappeared and she felt more comfortable.

The national cancer unit was based in the capital city over 250 km away from her village, and once her pain was controlled and the radiotherapy was finished, she wanted to go back home. As well as being nearer to her children, she could not afford the expense of being in hospital, and she was worried that the children would not be being looked after properly by her elderly mother-in-law. She was aware of her diagnosis of cancer, and the doctors were concerned that she might have an underlying condition of HIV, particularly as her husband had died of "unknown causes." She was, however, reluctant to have an HIV test due to the stigma that she may experience if it came back positive, and due to the advanced stage of her disease, having an HIV diagnosis was unlikely to alter the course of treatment. She was worried about the future of her two children aged 12 and 14 years, and concerned whether her mother-in-law would be able to support them if she died. These problems were addressed with repeated talks with Grace about issues surrounding the health of her children, both of whom seemed to be in good health. Grace was referred to a local home-based care team in her village and was advised as to how she could continue to access oral morphine for pain control, and she was discharged 10 days after having been admitted. She was supported by the home care team, the community, and spiritual leaders at home until she died 5 weeks later with her symptoms under control and having made arrangements for her children's care.

This case report emphasizes what palliative care is about. It is about management of pain and other symptoms, but it is also about psychological, social and spiritual problems. It is about the coordination and continuity of care in different settings and across the disease trajectory. It is about interdisciplinary and cross-sectional team work involving staff from different health care professions as well as volunteer services, including caregivers in their role as partners in the team as well as in their role as family members who require care and support.

How important is the assessment of the patient?

A thorough baseline assessment before the initiation of palliative care interventions as well as regular follow-up evaluations are paramount to ensuring adequate relief of symptoms and distress, and to adapting treatment to the individual patient. The initial assessment will describe the needs of the patient and form the basis not only for a drug regimen, but also for a palliative care plan tailored to individual needs and the patient's situation and context. It is also important to try to assess the cause of any pain or symptoms that the individual might be experiencing, and if the cause is treatable, e.g., an opportunistic infection, then it is important to treat the cause as well as manage the symptom.

What should be done for baseline assessment?

The baseline assessment should include a minimum set of information elicited by the health professional to help provide information about the context of care, e.g., age, sex, underlying disease, care setting, ongoing therapy (medical as well as traditional and complementary therapies), and previous treatments. The description of the care setting should include where the patient lives, who provides care, how many people there are at home, and an overview of financial and emotional resources and the needs of the patient and family. A sociogram can offer a rapid overview of family relations, and important events in the family history including any history of illness.

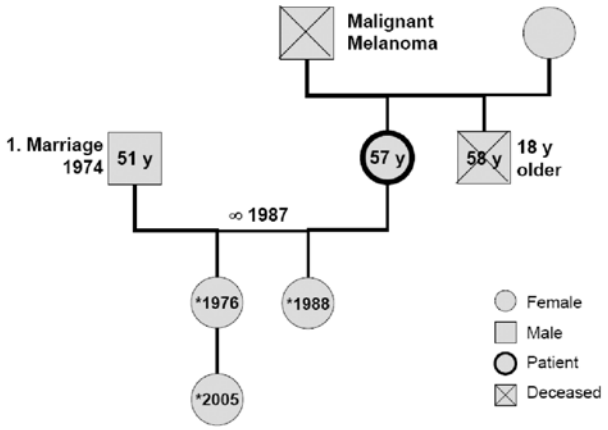

Fig. 1. Sociogram of a family setting of a woman with malignant melanoma.

Along with information about the context of care, the baseline assessment should not be restricted to physical symptoms, but should include several dimensions: physical, psychological, social, and spiritual deficits and resources. Many symptoms such as pain, dyspnea (difficulty breathing), nausea, or fatigue depend on subjective feelings rather than on objective measurable parameters, and so self-assessment by the patient is preferable. Self-assessment can be done with short symptom checklists such as the Edmonton Symptom

Assessment Score (ESAS), which uses numerical rating scales (NRS) or visual analogue scales (VAS) to assess intensity of the most important symptoms. The palliative care outcome score (POS) is a more comprehensive instrument that tries to include all dimensions of care in 12 questions. An African version has been developed that has been used with good effect in resource-poor settings. However, many patients with advanced diseases and with declining cognitive and physical function will not be able to complete even short self-assessment instruments. Assessment by caregivers or staff is usually a close substitute for the patient's self-assessment and should be implemented for such patients.

Assessment of psychological, spiritual, and social issues can be more complex, with limited tools being available to aid the health care professional. However, simple tools can be used for this purpose, such as FICA for assessing spiritual needs, i.e., Faith or beliefs, Importance and influence, Community, and Addressing the issues.

Performance status is an important parameter because it predicts needs. Performance status is also well suited for evaluation and monitoring of services, as it describes the patient population cared for. The Eastern Cooperative Oncology Group (ECOG) Score is an easy four-step categorical scale which is also implemented in the POS (Fig. 2).

0 = Fully active, able to carry on all pre-disease performance without restriction.
1 = Restricted in physically strenuous activity but ambulatory and able to carry out light work, e.g., light housework, office work.
2 = Ambulatory and capable of all self-care but unable to carry out any work activities. Up and about more than 50% of waking hours.
3 = Capable of only limited self-care, confined to a bed or chair more than 50% of waking hours.
4 = Completely disabled. Cannot carry on any self-care. Totally confined to a bed or chair.

Fig. 2. Eastern Cooperative Oncology Group (ECOG) Scale.

What follow-up assessments are needed for re-evaluation?

Assessment is an ongoing process, and so after the initiation of treatment, regular re-evaluation is very important. The efficacy of any treatment given for symptom relief has to be monitored, and the treatment, including drug regimen, has to be adapted according to its effect. After the initial phase, with stable symptom relief, regular re-assessment should be maintained, as further deterioration from the underlying disease is to be expected. Cancer patients or HIV/AIDS patients receiving palliative care should be seen weekly, or at least monthly if the situation is stable, by the health care professional. Follow-up assessments can be brief, but should include short symptom checklists to monitor whether new symptoms have appeared. Treatment for new symptoms and problems should be initiated. The POS can be used on a regular basis to assess the patient's status, and ongoing therapies should also be re-evaluated regularly, to see whether they still are indicated or whether careful dose reduction or even withdrawal might be advisable. However, it should be noted that often drugs for the relief of pain, dyspnea, and other symptoms must be continued until the time of death. Symptomatic treatment can be discontinued if treatment of an underlying cause of the symptoms is possible (for example an opportunistic infection in patients with HIV/AIDS).

Following the death of the patient, an evaluation of the overall efficacy of the palliative care delivered is useful for quality assurance purposes. The easiest way is to ask caregivers and family members for an overall evaluation of the patient's care a few weeks or months after the death of the patient, using a simple categorical scale (overall satisfaction with care: very unsatisfied, unsatisfied, neither unsatisfied nor satisfied, satisfied, or very satisfied).

Symptom relief

Why is symptom relief so important?

Management of pain and other symptoms is an essential part of palliative care. With progression of the underlying disease, most patients suffer from physical and psychological symptoms. Cancer, HIV/AIDS, and other chronic infections such as tuberculosis may result in a plethora of symptoms, with severe impairment from pain, dyspnea, nausea and vomiting, constipation, or confusion. Most patients with advanced disease and limited life expectancy suffer from weakness and tiredness (fatigue), caused either by the disease or its treatment. Coping with the diagnosis and prognosis may lead to spiritual and psychological distress, anxiety, and depression. These symptoms can be treated, and with the alleviation of the symptom load, quality of life will be restored.

The following section will provide an overview on the management of the most important and most

frequent symptoms (Table 1). More detailed information on assessment and treatment of symptoms and on other areas of palliative care can be found in the clinical guide to supportive and palliative care for HIV/AIDS in sub-Saharan Africa, and in the WHO Integrated Management of Adult Illnesses Palliative Care module and related materials.

Pain management in palliative care follows the rules of cancer pain management, with analgesic medications according to the principles of the World Health Organization at the center of the therapeutic approach. Opioids such as oral morphine are the mainstay of pain management in palliative care in low-resource settings because they are relatively inexpensive and because effective palliative care is not possible without the availability of a potent opioid. Detailed information is available in Chapter 6.

Is treatment of other symptoms similar to pain management?

Whilst there is no similar tool to the WHO analgesic ladder to help treat other symptoms, many of the principles applied to the pain management can also be applied to other symptoms. For example, reverse what is reversible and treat the underlying cause without increasing the symptoms; use nonpharmacological drug interventions—adjunctively or alone, as appropriate; use medications specific to the types of symptoms; and address associated psychosocial distress. Medication for symptom management should also be given by the clock according to the different dosages available and where possible by mouth, thus making it easier for people to continue with their medications at home, where there is no health professional to give them injections.

How should you treat dyspnea?

Whereas opioids are well established as the mainstay of pain management, it is less well known that opioids also are very effective for the treatment of dyspnea. In opioid-naive patients, oral morphine (5–10 mg) or subcutaneous morphine (2.5–5 mg) will provide quick relief and may be repeated as required. Other opioids can be used for this indication as well, with equipotent dosage. Patients already receiving opioids for pain should have a dose increase to alleviate dyspnea. Continuous dyspnea should be treated with a continuous opioid medication, following similar dose-finding rules as for pain management, although mostly with lower starting dosages.

Respiratory depression is a side effect of opioids, but it does not contradict the use of opioids for dyspnea. Dyspnea is most often related to elevated carbon dioxide in the arterial blood, and less to reduced oxygen. Opioids diminish the regulatory drive caused by elevated carbon dioxide levels, and in consequence patients will feel less hunger for air, even if breathing is not improved. Opioids also reduce pain and anxiety, thus alleviating stress-induced dyspnea.

Dyspnea in cancer patients may also be caused by mechanical impairment, for example from pleural effusion. Mechanical release with pleural puncture will produce rapid relief. Dyspnea can also be related to severe anemia, leading to reduced oxygen transport capacity in the blood, and blood transfusions will alleviate dyspnea in severely anemic patients, though most often only for a few days until the hemoglobin count falls again. Oxygen will be helpful for control of dyspnea only in a minority of patients; however, other nonpharmacological interventions may help, such as repositioning of patients e.g., sitting in an upright position.

In most patients simple measures such as comforting care, allowing free flow of air, for example by opening a window or providing a small ventilator or fan, will be very effective in the treatment of dyspnea.

How should you treat nausea?

Nausea and vomiting can be treated with antiemetics such as metoclopramide or low-dose neuroleptics such as haloperidol. Corticosteroids can be most effective if gastrointestinal symptoms are caused by mechanical obstruction from inflammation or cancer. Nondrug interventions include nutritional counseling. Acupuncture or acupressure at the inner side of the forearm (acupuncture point "Neiguan") is very effective in some patients and has been proven to be as effective as antiemetic drugs in clinical trials.

How should you treat constipation?

Constipation may be caused by intestinal manifestations of the underlying disease, by drugs such as opioids or antidepressants, but also by inactivity, a low-fiber diet, or low fluid intake. Prophylactic treatment with laxatives should be prescribed for every patient receiving chronic opioid therapy. In contrast to other adverse events such as sedation, which most patients report only for the first few days after initiation of opioid therapy or a dose increase, patients do not develop tolerance to constipation. The peripheral opioid antagonist methylnaltrexone

Table 1
The essence of symptom control:
first-line medication for predominant symptoms

Medication	Dosage	Drug Class	Comments
Dyspnea			
Morphine	As required, or 10–30 mg/d initially p.o., titrate to effect; maximum dosage may exceed 600 mg/d	Opioid (μ-agonist)	AE: constipation, nausea, sedation, cognitive impairment
Hydromorphone	As required, or 4–8 mg/d initially p.o., titrate to effect, maximum dosage may exceed 100 mg/d	Opioid (μ-agonist)	AE: constipation, nausea, sedation, cognitive impairment
Lorazepam	As required, or 1–5 mg/d sublingual	Benzodiazepine	Cumulation with repeated use
Respiratory Tract Secretions			
Hyoscine butylbromide (butylscopolamine)	As required, 20–40 mg s.c. (4-hourly)	Antimuscarinergic drug (peripheral action)	No antiemetic effect
Hyoscine hydrobromide (scopolamine)	As required, 400 μg s.c.	Antimuscarinergic drug (central and peripheral action)	Antiemetic effect; AE: sedation
Nausea and Vomiting			
Metoclopramide	30 mg/d; high dose: up to 180 mg/d	5-HT_4 antagonist	Extrapyramidal AE; do not use in patients with gastrointestinal obstruction!
Haloperidol	2 mg/d up to 5 mg/d	Neuroleptic drug	Extrapyramidal AE
Constipation			
Macrogol	1 bag orally		
Sodium picosulfate	10–40 drops orally		
Octreotide	0.3–0.6 mg/d s.c.		Reduces gastrointestinal secretions effectively, indicated for patients with gastrointestinal obstruction
Methylnaltrexone	0.8–1.2 mg/d	Opioid antagonist (peripheral action)	Effective for opioid-induced constipation
Fatigue, Weakness			
Dexamethasone	12–24 mg/d initially, stepwise reduction after a couple of days	Corticosteroid	Gastric ulcers, hallucinations, nightmares, weight gain, only effective for a restricted time period
Anxiety			
Lorazepam	1–5 mg/d	Benzodiazepine	AE: paradoxical effects
Mirtazapine	15 mg initially, stepwise increase after 2–3 weeks up to 45 mg/d	Antidepressant (SNRI)	Also effective for treatment of panic attacks, pruritus; AE: sedation, increased appetite, liver dysfunction
Depression			
Mirtazapine	15 mg initially, stepwise increase after 2–3 weeks up to 45 mg/d	Antidepressant (SNRI)	Also effective for treatment of anxiety, panic attacks, pruritus; AE: sedation, increased appetite, liver dysfunction
Methylphenidate	5 mg in the morning initially, stepwise increase to 30 (40) mg/d	Stimulant	AE: agitation, restlessness, extrapyramidal effects, tachycardia, arrhythmia
Agitation, Confusion			
Haloperidol	2 × 1 mg, up to 20 mg/d	Neuroleptic drug	AE: extrapyramidal effects
Levomepromazine (methotrimeprazine)	25–50 mg, up to 200 mg/d	Neuroleptic drug	AE: sedation, anticholinergic effects

Abbreviations: AE = adverse effect; SNRI = serotonin norepinephrine reuptake inhibitor.

offers a selective and effective option for treatment of opioid-induced constipation, but high costs will prevent its use in resource-poor settings. Nondrug interventions such as increased activity, more fluid intake, or change of diet usually are very effective, if appropriate for the patient's condition.

How should you treat fatigue?

Fatigue has been named as the most frequent symptom of cancer patients, and it is a predominant feature in noncancer palliative care patients as well. As the concept of fatigue is often not clearly understood by patients or by all health care professionals, it is recommended to consider the symptoms tiredness and weakness instead of fatigue. However, there are only a few medical interventions for these symptoms. Treatment with erythropoietin, where available, has been used with good effect in cancer patients, but in the palliative care setting with reduced life expectancy there seems to be no indication for erythropoietin. Drugs such as methylphenidate and modafinil are under investigation. However, the most effective medication seems to be dexamethasone or other steroids. Their effect tends to wear off within a few days or weeks, and often is accompanied by adverse events, so steroids should be reserved for situations where a clear goal is visible within a short time frame, such as a family celebration.

Reduction of other medications may alleviate tiredness dramatically, and a review of the drug regimen is advocated in patients with reduced performance status, as many medications may not be required any more. In selected patients with severe anemia, blood transfusions are an option to reduce tiredness and weakness, with repeated transfusions even over a prolonged period of time.

However, for most patients, nondrug interventions will be effective, such as counseling, energy conserving and restoration strategies, and keeping a diary of daily activities. Physical training has been shown to reduce fatigue effectively. Physical activity is possible even for patients with advanced disease, although it has to be adapted to reduced performance status and cognitive function.

How should you treat anxiety and depression?

Anxiety and depression are among the major psychological problems in palliative care. Patients facing the diagnosis of an incurable disease and limited prognosis may have every right to feel anxious and depressed. However, these symptoms may overburden the patient and will then require treatment to restore quality of life for the remainder of the lifespan.

Anxiety may be most pronounced at night, preventing sleep and adding to tiredness during the day. Benzodiazepines at night provide a good night's rest and prevent endless brooding. Lorazepam offers a profile with rapid onset and little hangover the next day, but other sedatives will do as well. Treatment with benzodiazepines will also help with the treatment of dyspnea and other symptoms, as these symptoms may have been augmented by anxiety.

Some patients with advanced disease suffer from major depression and require treatment with antidepressants. Mirtazapine is included in the IAHPC list of essential drugs for palliative care. Mirtazapine is also indicated for anxiety and panic attacks, and has been reported to alleviate pruritus. However, for treatment of depression, other antidepressants will do as well. Selective serotonin reuptake inhibitors (SSRIs) should be preferred as they produce less side effects compared to older tricyclic antidepressants. Effect of antidepressant therapy usually will take 2–3 weeks, and as treatment should be started at a low dose with stepwise titration until effective, many patients with reduced life expectancy will not live long enough to benefit from antidepressants. For these patients methylphenidate is an alternative, as the onset of action takes only a few hours.

However, many patients will suffer not from major depression, but from feeling depressed, which is not the same. A feeling of sadness and grief may be completely appropriate and may even help with coping with the disease. Treatment with antidepressants for these patients may impede coping and add burdensome side effects such as dry mouth or constipation. The decision to treat depression therefore requires careful balancing of effectiveness and side effects.

How should you treat agitation and confusion?

In the final phase of life, agitation and confusion are frequent symptoms that can cause considerable stress not only on the patient, but also on caregivers and staff. Neurological causes may include focal seizures, ischemic insult, cerebral bleeding, or brain metastases. Many drugs as well as withdrawal of drugs or more frequently of alcohol may lead to delirium, typically with fluctuating symptomatology after sudden onset. Fever, infection, electrolyte disturbance such as hypercalcemia, or dehydration also may trigger or aggravate delirium.

Neuroleptic medication may be required, with haloperidol as a first-line approach. High dosages may be required, with doses as high as 20–30 mg per day. Other neuroleptics such as levomepromazine have more sedative properties and may be beneficial in severely agitated patients. For patients with HIV disease, HIV-related brain impairment can cause agitation and confusion earlier on in the disease trajectory, and thus similar symptoms may have to be controlled prior to the final phase of life.

Emergency interventions

What constitutes an emergency in palliative care?

Exacerbation of pain and other symptoms as well as severe psychological distress with anxiety or even panic may lead to emergency situations that require immediate action. In these emergencies, the onset of symptom relief should not be delayed unduly by prolonged assessment or differential diagnosis. However, the usual medical emergency procedures may also be detrimental, for example when pain exacerbation leads to a hospital admission with transport time as well as radiographic and laboratory investigations, but without analgesic intervention or comforting care.

Emergencies that have to be treated rapidly and adequately are exacerbations of preexisting symptoms, new symptoms with sudden and intense onset, or rare complications such as massive hemorrhage. Individual treatment plans in palliative care should try to foresee such emergencies and provide adequate interventions. Prescription (or even better, provision) of rescue medication for emergencies is especially important when health care professionals are not available out of office hours, and care has to be delivered by auxiliary staff or family caregivers.

What is rescue or breakthrough medication?

Rescue or breakthrough medication should be prescribed for patients with advanced disease, where exacerbations of pain or other symptoms are possible, and rapid treatment of these exacerbations is required. Rescue medications can include different drugs, but for most patients they should include at least an opioid with fast onset for treatment of pain, dyspnea, and anxiety as well as a benzodiazepine such as lorazepam for the treatment of dyspnea, anxiety, and agitation (Table 2).

Respiratory secretions may lead to labored breathing in dying patients, and may cause distress in patients as well as in caregivers. Anticholinergic drugs such as hyoscine butylbromide may alleviate this "death rattle" quickly.

For all drug interventions, the route of administration should be considered. Oral application may be much easier if no professional help is available, but in some patients oral intake is not possible. Opioids as well as many other drugs used in palliative care can be injected subcutaneously, with little risk of complications and with a faster onset of action than with oral application. Intravenous application offers the option for rapid titration with small bolus administrations if trained staff are available.

What should be done in the case of massive hemorrhage?

Cancer growth in the skin or mucous membranes may lead to excessive bleeding if major blood vessels are ruptured. This can manifest with sudden onset or with

Table 2
The essence of symptom control: emergency intervention

Medication	Dosage	Drug Class	Comments
Rescue Medication (Given as Required)			
Morphine 10 mg	10–20 mg orally 10 mg s.c. (or i.v. in small steps)	Opioid (μ-agonist)	Indication: pain, dyspnea
Hydromorphone	1.3–2.6 mg orally 2–4 mg s.c.	Opioid (μ-agonist)	Indication: pain, dyspnea
Hyoscine butylbromide 40 mg	20 mg s.c.	Antimuscarinergic drug	Indication: respiratory tract secretions
Lorazepam 1 mg	1 mg sublingually	Benzodiazepine	Indication: agitation, anxiety
Palliative Sedation			
Midazolam	3–5 mg/h s.c., i.v. or 3–5 mg bolus as required	Benzodiazepine	Paradoxical effect/ inadequate effect

increasing intensity, or with sudden vomiting of clotted blood from gastrointestinal bleeding. With minor bleeding sometimes blood transfusions may be indicated. For more severe bleeding, benzodiazepines or morphine via subcutaneous bolus administration may be indicated, but often they will not take effect fast enough. With massive hemorrhage the patient will quickly become unconscious and die with little distress, and treatment should be restricted to comfort measures. Enough towels or similar material should be available to cover the blood.

What is palliative sedation?

Rarely, patients with extreme distress from pain, dyspnea, agitation, or other symptoms that are resistant to palliative treatment, or do not respond fast enough to adequate interventions, should be offered palliative sedation. This means that benzodiazepines are used to lower the level of consciousness until distress is relieved. In some patients deep sedation is required, rendering the patient unconsciousness. However, for other patients mild sedation may be enough, so that patients can be roused and can interact with families and staff to some degree. Intravenous or subcutaneous midazolam is used most often, as it can be titrated to effect easily.

It should be realized that palliative sedation is the last resort if symptomatic treatment fails. Before the initiation of this treatment, other treatment options have to be considered, and the priorities of the patient should be clarified. Some patients prefer to suffer from physical symptoms instead of losing cognitive capacity, and sedation should only be initiated if the patient agrees. Effective services will find an indication for sedation in only a few selected patients with very severe symptoms.

Psychosocial and spiritual care

What is the impact of psychosocial issues on medical care?

Psychosocial issues are often neglected by medical staff, even though they are paramount for many patients. Fears about the progression of the disease, about death and dying, about financial problems, or about stigmatization with diseases such as HIV/AIDS may overwhelm patients, alienate them from their family and friends, and often aggravate the impact of physical symptoms. For most patients in resource-poor countries the loss of support is an immediate implication of a life-threatening disease, often endangering the survival of the patient as well as of the family. Social support that provides the means to sustain basic requirements is as mandatory as the medical treatment of symptoms.

Most patients with life-threatening disease also have spiritual needs, depending on their religious background and cultural setting. Spiritual support from caregivers as well as from specialized staff, for example religious leaders, may be helpful.

How do you communicate bad news?

Palliative care staff should have special communication skills. Health care professionals should be able to collaborate with other staff and volunteers who care for the patient, and agree on treatment regimens and common goals for the patient. They must also be able to communicate with patients and families on difficult topics, for example ethical decisions such as treatment withdrawal or withholding of treatment. Specific models are available, for example the SPIKES model for breaking bad news (Table 3).

Table 3
SPIKES model for breaking bad news

Setting	Choose the setting for the talk, talk on same eye level with patient, avoid disturbances and interruptions, allow for family members to be present.
Perception	Check the capacity of the patient, impairment from medication or from disease, or from interaction with family members, use verbal and nonverbal cues for perception.
Invitation	Ask the patient about his level of information, what does he know about his disease and about the topic of the talk, and ask the patient how much he wants to know.
Knowledge	Inform the patient about the bad news, in a structured way with clear terminology, allow for questions and give as many details as the patient requires.
Empathy	Leave time for emotional reactions of the patient, explore emotional reactions and react empathically.
Summary	Provide a concise summary, if possible with some written summary, and offer a follow-up talk if possible.

How do you provide bereavement support?

Bereavement support is an important, yet often forgotten, part of palliative care provision, which should not end with the death of the patient. Grief and loss are expressed in a multiplicity of words and languages by different peoples. A wealth of diverse ritual serves to guide people in societies through the grief process, and it is important for the health professional to be aware of such rituals. Grief not only affects relatives, but also patients themselves, who may experience anticipatory grief prior to their death as they grieve the various losses that they are experiencing such as the loss of their future and the loss of seeing their children grow up. Patients need support to work through some of these issues prior to their death and to plan for the future of their loved ones, where possible.

Many different factors can affect the bereavement process for family members, including their relationship with the person who died, the way that they died, whether they were experiencing symptoms and were seen to be suffering, stigma, a lack of disclosure about their illness, local cultural practices and beliefs, personality traits, other stresses that they may also be experiencing, and bereavement overload if they have lost several friends and relatives in a short space of time. Ongoing bereavement support may be provided to relatives, either by the palliative care team or by referral to local community networks and support systems. It is important that the need for bereavement support be recognized and support provided as appropriate.

Ethical decision making

Whereas guidelines and recommendations are available for most areas of symptom control, there are some issues in palliative care that are loaded with ethical implications.

Are nutrition and fluid substitution necessary if oral intake is not possible?

Patients and more often other caregivers and health care professionals insist on enteral or parenteral nutrition or at least fluid substitution if patients are no longer able to eat or drink. If the therapist does not comply with this wish, it is often considered as inhumane, as the patient then will starve or die of thirst. Nutrition often has an overwhelming symbolic significance, and as long as the patient is nourished, caregivers will perceive a chance for the patient to get well. This significance may be supported by medical staff who explain that the withholding of anticancer therapies is linked to the poor nutritional status of the patient. However, it has to be realized that cachectic patients with cancer or with HIV/AIDS most often do not benefit from nutrition. In most cases, a catabolic metabolism is the major reason for cachexia, and the provision of additional calories does not change that status. Patients in the final stage of the disease may even deteriorate with parenteral fluid substitution, when edema or respiratory secretions are increased. Thirst and hunger, on the other hand, are not increased when fluids and nutrition are withheld. In many cases, and nearly always in dying patients, nutritional supplements, parenteral nutrition, and fluid replacement are not indicated and should be withdrawn or withheld. If necessary, small amounts of fluid (500–1000 mL) may be infused with a subcutaneous line.

How should we react if patients ask for hastened death?

Palliative care by definition neither hastens nor postpones death. Active euthanasia is not a medical treatment and cannot be part of palliative care. However, there are a few patients receiving palliative care who ask for assisted suicide or for active euthanasia or for other forms of hastened death.

In most countries, withholding or withdrawing life-sustaining treatment is legally and ethically acceptable, and so treatment reduction may offer an option. In selected cases with intolerable suffering, palliative sedation may be indicated. However, for most patients asking for hastened death, a more detailed exploration and more empathic care should be offered. Often the statement “I do not want to live anymore” means “I do not want to live like this anymore,” and communication about problems or fears may help to alleviate the wish for hastened death. For most patients it is possible to find a solution that allows them to spend the rest of their days with an acceptable quality of life.

References

[1] Baile WF, Buckman R, Lenzi R, Glober G, Beale EA, Kudelka AP. SPIKES: a six-step protocol for delivering bad news: application to the cancer patient. Oncologist 2000;5:302–11.
[2] Buccheri G, Ferrigno D, Tamburini M. Karnofsky and ECOG performance status scoring in lung cancer: a prospective, longitudinal study of 536 patients from a single institution. Eur J Cancer 1996;32:1135–41.
[3] Chang VT, Hwang SS, Feuerman M. Validation of the Edmonton Symptom Assessment Scale. Cancer 2000;88:2164–71.
[4] Conill C, Verger E, Salamero M. Performance status assessment in cancer patients. Cancer 1990;65:1864–6.

[5] Downing J, Finsch L, Garanganga E, Kiwanuka R, McGilvary M, Pawinski R, Willis N. Role of the nurse in resource-limited settings. In: Gwyther L, Merriman A, Mpanga Sebuyira L, Schietinger H, editors. A clinical guide to supportive and palliative care for HIV/AIDS in Sub-Saharan Africa. Kampala: African Palliative Care Association; 2006.
[6] Gwyther L, Merriman A, Mpanga Sebuyira L, Schietinger H. A clinical guide to supportive and palliative care for HIV/AIDS in sub-Saharan Africa. Kampala: APCA; 2006.
[7] Hearn J, Higginson IJ. Development and validation of a core outcome measure for palliative care: the palliative care outcome scale. Palliative Care Core Audit Project Advisory Group. Qual Health Care 1999;8: 219–27.
[8] Materstvedt LJ, Clark D, Ellershaw J, Forde R, Gravgaard AM, Muller-Busch HC, Porta i Sales J, Rapin CH. Euthanasia and physician-assisted suicide: a view from an EAPC Ethics Task Force. Palliat Med 2003;17: 97–101; discussion 102–79.
[9] Nieuwmeyer SM, Defilippi K, Marcus;C., Nasaba R. Loss, grief and bereavement. In: Gwyther L, Merriman A, Mpanga Sebuyira L, Schietinger H, editors. A clinical guide to supportive and palliative care for HIV/AIDS in Sub-Saharan Africa. Kampala: African Palliative Care Association; 2006.
[10] Powell RA, Downing J, Harding R, Mwangi-Powell F, Connor S. Development of the APCA African Palliative Outcome Scale. J Pain Symptom Manage 2007;33:229–32.
[11] Puchalski C, Romer AL. Taking a spiritual history allows clinicians to understand patients more fully. J Palliat Med 2000;3:129–37.
[12] Sepulveda C, Marlin A, Yoshida T, Ullrich A. Palliative care: the World Health Organization's global perspective. J Pain Symptom Manage 2002;24:91–6.
[13] World Health Organization. Cancer pain relief and palliative care—report of a WHO expert committee. WHO Technical Report Series No. 804. Geneva: World Health Organization; 1990.

Websites

World Health Organization (2004) Integrated Management of Adult Illnesses, palliative care: symptom management and end of life care, http://www.who.int/3by5/publications/documents/imai/en/ (Accessed November 25, 2008).