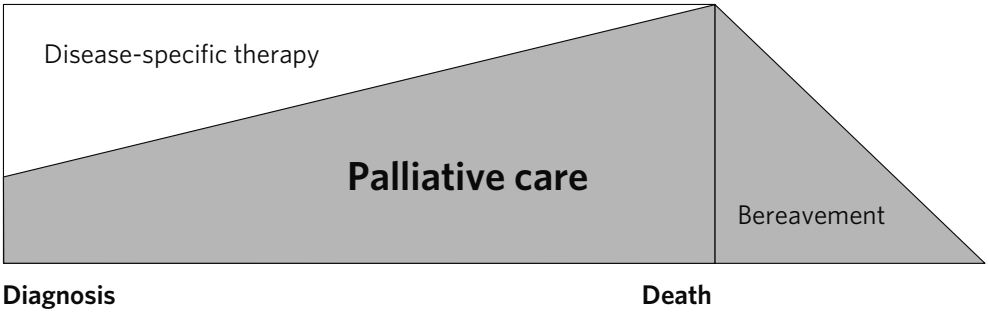
CHAPTER 2
Palliative Care and Chronic Care

Palliation is the aspect of healthcare concerned with the prevention and relief of suffering rather than treatment of specific diseases. Palliative treatments aim primarily to improve the quality of life, but may also include life-extending therapies. Chronic diseases fall along a spectrum of symptom burden and risk of death. Palliative care is an integral component of treating patients with many chronic diseases, particularly in their more severe manifestations. These diseases and their treatments can cause distressing symptoms, such as pain, dyspnea, and nausea. The suffering due to these symptoms usually remains unrelieved under conditions of extreme poverty and is exacerbated by the terrible financial and psychosocial burden of illness in rural sub-Saharan African villages. In this setting, palliation becomes an essential task for the family and the health care provider, one that tests the limits of our commitment to another person's well-being. Palliative care should be provided throughout the course of a disease and not just at the end of a patient's life (see FIGURE 2.1). The balance of disease-specific and palliative therapies depends on the nature of the underlying pathology.

FIGURE 2.1 Diagram of Palliative Care throughout the Course of Illness and Bereavement (Adapted from WHO)[1]



In this chapter, we describe the essential role palliative care plays in delivering effective chronic care for non-communicable diseases in resource-poor settings. In other sections of the handbook, we have attempted to incorporate palliative treatments into each disease-specific approach. Rwanda has recently approved palliative care policies designed to make pain control widely available. However, this effort is still in a nascent stage. We have based our material on our team's palliative care experiences in Vietnam and Uganda, which have well-developed programs.[2-5] Rwanda aims to make palliative care a fully integrated part of chronic care services.

2.1 History and Philosophy of Palliative Care Efforts in Resource-Poor Settings

To many, palliation has become synonymous with end-of-life care. This is because, in wealthy nations, palliative care has developed as an alternative to disease-modifying treatments of unlikely benefit for patients with advanced disease. It is often the path chosen at the end of a long battle with an illness at a time when aggressive measures to extend life clearly seem inappropriate.

However, in any setting, attention to symptom relief throughout the disease course should complement efforts to modify the disease and extend life. In fact, recent data suggests that early palliative care can improve both the longevity and the quality of life of some cancer patients.[6] A narrow conception of palliation is even less relevant in places where patients have had access to neither life-prolonging treatment nor palliation.[7]

Palliative care should never be considered an alternative to disease-modifying treatments for patients reasonably likely to benefit from them. Efforts to provide palliative care to AIDS patients, for example, without simultaneous efforts to provide HIV prevention, diagnosis, and antiretroviral (ARV) treatment, are never justified. The reverse is true as well. Programs that offer only one or the other do not provide optimum care and create an unjustifiable dichotomy between palliative and disease-modifying or curative treatments. In fact, the two approaches are interdependent—ARVs are often the most effective means of relieving the symptoms of HIV-related disease, and at the same time palliation of HIV-related symptoms and ARV side effects can increase ARV adherence and extend life. Moreover, HIV remains a chronic disease with significant morbidity and mortality even with therapy, and ARV therapy itself is associated with serious health problems over time. Policies to ensure comfortable and dignified deaths are widely viewed as a human right.[7-9]

Although there is no longer debate about the need for universal access to ARVs, there are still many treatments for non-communicable diseases that are not readily available in resource-poor settings. Of course, there are limits. All medical interventions fall within a spectrum both in terms of cost and efficacy. When do we say a therapy is too expensive in light of the expected benefit? Even in high-resource settings, there are debates about the cost and benefits of specific interventions and whether there is a societal obligation to provide them. Countries like the United Kingdom have attempted to answer this question through formal cost-effectiveness analyses and have developed national guidelines.[10] Similar efforts have been undertaken for resource-poor settings.[11]

As we have learned from the global experience with ARVs, it is often possible to decrease the price of effective therapies through advocacy and collective bargaining. This observation has made effectiveness a more important criterion than cost in determining the appropriate scope of services for a population. Furthermore, the total cost of high-impact, high-cost interventions may not be very significant at country level, if the prevalence of the disease is low. At the same time, the total price of low-cost, low-impact therapies may be very high if the condition is very prevalent (see **TABLE 2.1**). In Rwanda, the Ministry of Health has worked to increase access to high-impact therapies. In some instances, such as renal transplant and dialysis, this has been particularly challenging. Low-impact, high-cost treatments, on the other hand, are controversial even in very wealthy countries. We have not worked to make such treatments available in the Rwandan setting.

TABLE 2.1 Cost/Impact Matrix of Medical Interventions, with Examples

	High impact of therapy	Low, marginal impact of therapy
High cost	• Anti-tuberculosis drugs for multidrug-resistant TB • ARVs for HIV • Cardiac surgery • Renal transplant • Dialysis	• Erlotinib for metastatic pancreatic cancer • Implantable cardioverter defibrillators for cardiomyopathy • Tiotroprium bromide for COPD • Long-acting, patented preparations of shorter-acting medications
Low cost	• Morphine for pain • Bed nets for malaria prevention • Oral rehydration therapy for diarrhea	• Hydrochlorothiazide for Stage 1 or 2 hypertension without high-risk features

Organizations such as the WHO recognize palliative care as an essential component of the treatment of chronic diseases such as cancer and HIV/AIDS. A recent WHO study in five sub-Saharan African countries found that roughly 1% of their populations were in need of end-of-life palliative care each year.[1] They also concluded that because of patient preference and cost considerations, home-based palliative care was the most appropriate model for most patients. The WHO has developed a Palliative Care Guideline Module as part of its package of Interim Guidelines for First-Level Facility Health Workers in Low-Resource Settings.[12] It covers in detail how to treat various common symptoms.

2.2 Community Health Workers and Common Palliative Care Interventions in the Treatment of Chronic Disease

Vertical palliative care programs have attempted to fill an unmet need for palliative services in some African countries. These programs often acknowledge the benefits of integration into existing health systems,

but frequently find that this is difficult to achieve. Rwanda has sought to break this pattern by integrating palliative care into chronic care services at the district-hospital, health-center, and community level.

In this model, a central palliative care unit will provide oversight, including training, monitoring, and supervision. It also will ensure both that opioid pain medication is accessible by anyone in need and that the risk of opioid diversion for illicit purposes is minimized. This unit may be located within university teaching hospitals. At district level, palliative care will be integrated into existing functions of physicians and advanced NCD nurses. Physicians will perform initial evaluations of patients in need of home-based palliative care and prescribe medications, including oral morphine. NCD nurses will then be charged with monitoring these patients and with providing oversight of health center–based nurses. At the health-center level, nurses will adjust prescriptions and provide oversight and training to the community health workers. All essential palliative care medications should be available at the health-center level in order to maximize patient access. At the community level, each village in the country will be staffed by community health workers devoted to treating patients with chronic disease. These community health workers will provide adherence support as well as palliative care for patients with chronic disease. Palliative interventions will include providing clinical care and emotional support to patients throughout the course of their chronic illnesses, as well as helping to provide home-based end-of-life care for patients and their families. This community-based work complements efforts to address palliative needs in the clinic and hospital setting and will make possible a continuum of palliative care from the hospital to the home that is essential but rarely available in the developing world.

2.2.1 Assessment of Symptoms

True integration of palliation within a model of chronic disease care includes a thorough assessment of physical and psychosocial distress at the time of disease diagnosis. These elements should be reviewed on each return visit as part of the assessment of disease control. The needs of the family members helping to care for the patient also should be assessed intermittently. Often, palliative efforts will include delivering material support to families impoverished by the patient's illness, including help with housing, food, and school fees. Addressing the social needs of these patients and their families requires coordination with government ministries engaged in agriculture, education, and social welfare.

Palliative care researchers have developed a validated questionnaire, which has been tested in rural sub-Saharan African settings (see **TABLE 2.2**).[13] These questions will not be applicable for all patients with chronic

illness, such as those with mild asthma or hypertension. We have incorporated these questions into our clinical forms where appropriate in the Rwandan NCD clinics. We are in the process of developing more simplified tools for assessment of home-based symptom management by community health workers.

TABLE 2.2 Symptom Assessment Scale (Adapted from the African Palliative Outcomes Scale)[13]

Questions for patient:	
Q1. Please rate your pain during the last 3 days	0 (no pain) – 5 (worst/overwhelming pain)
Q2a. Have any other symptoms (e.g., nausea, coughing, or constipation) been affecting how you feel in the last 3 days?	0 (no, not at all) – 5 (overwhelmingly)
Q2b. If so, please rate each symptom during the last 3 days: Dyspnea? Nausea or vomiting? Constipation? Diarrhea? Others? (specify)	 0 (no, not at all) – 5 (overwhelmingly) 0 (no, not at all) – 5 (overwhelmingly) 0 (no, not at all) – 5 (overwhelmingly) 0 (no, not at all) – 5 (overwhelmingly) 0 (no, not at all) – 5 (overwhelmingly)
Q3. Have you been feeling worried about your illness in the past 3 days?	0 (no, 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 (no, 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. Over the past 3 days, have you had enough help and advice for your family to plan for the future?	0 (no, not at all) – 5 (as much as wanted)
Questions for family caregiver:	
Q8. Over the past 3 days, how much information have you and your family been given?	0 (none) – 5 (as much as wanted) N/A
Q9. Over the past 3 days, how confident has the family felt caring for the patient?	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

2.2.2 Symptom Management

A wide array of chronic diseases afflicts our patients. Many cause one or more common, distressing symptoms. Therapies aimed at these nonspecific symptoms are an important component of chronic disease treatment algorithms. Here we touch on some of the principles outlined in the Integrated Management of Adult and Adolescent Illness Palliative Care Guideline Module, the Vietnam Ministry of Health Guidelines on Palliative Care for Cancer and AIDS Patients, and the Hospice Africa Uganda Palliative Medicine Guide.[2,5,12] Chemotherapy and radiation therapy, both of which have important roles in relieving pain and other

symptoms due to cancer, will be addressed in a forthcoming manual on cancer care and control.

2.2.3 Pain

Pain accompanies many chronic diseases and is a major cause of disability and suffering. However, access to pain relief typically is limited or nonexistent in resource-poor settings. Many countries severely restrict the use of morphine out of fear of opioid diversion or the creation of addiction among patients. A 2004 study by the International Narcotics Control Board revealed that countries with 80% of the world's population comprised only 6% of the world's total opioid consumption.[14] However several countries in sub-Saharan Africa, including Uganda, South Africa, and Rwanda have adopted policies to increase access to opiates.[15,16]

There are two major categories of chronic pain, which often require different therapies.

2.2.3.1 Nociceptive Pain

Nociceptive pain is caused by the stimulation of pain receptors at the end of normal sensory nerves that mediate pain. Nociceptive pain is further subdivided into somatic and visceral pain. Somatic receptors in the skin, soft tissues, muscle, or bone are stimulated, and the resulting pain usually is easy for the patient to localize and describe. Pain in the skin is often sharp, burning, or throbbing. Pain in the muscle is often gnawing or dull. Pain in the bone is also gnawing and dull, but can become sharp with movement. Visceral pain typically is not localized, but more diffuse, and may be referred to a site distant from the lesion. It may be dull or sharp and may produce a feeling of pressure. It is caused by stimulation of pain receptors in internal organs, including hollow viscera. It may be due to blockage, swelling, or stretching of the organs due to metastases, inflammation, or other causes.

2.2.3.2 Neuropathic Pain

Neuropathic pain is caused by damage to nerves or brain. Neuropathic pain is often described as burning or like an electric shock. There also can be numbness, tingling, or allodynia (pain resulting from a stimulus that normally is not painful, such as light touch) in the area innervated by the injured nerves. This type of pain is very common among our diabetic, cancer, and HIV/AIDS patients. Any kind of injury to nerve tissue can result in neuropathic pain, including compression or infiltration by tumor, ischemia from poor circulation (in diabetes mellitus), infection by varicella zoster or HIV virus, or neurotoxic medications, such as some cancer chemotherapy drugs and some ARVs, especially d4T (stavudine).

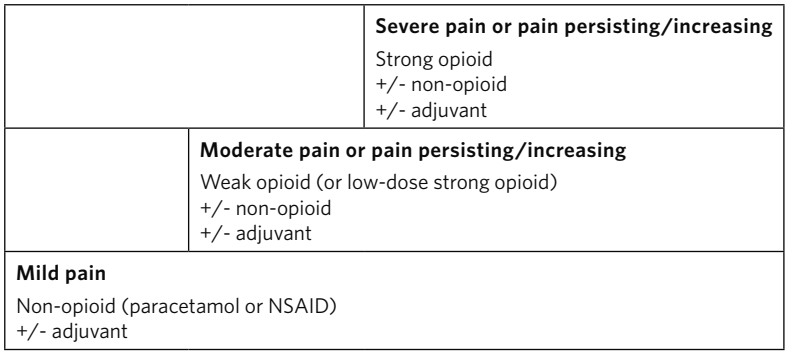
2.2.3.3 Principles of Pain Management

The following principles are important to successful treatment of pain:[1]

1. **WHO three-step pain-relief ladder.** Escalating therapy from a non-opioid (acetaminophen/paracetamol, ibuprofen, or aspirin) to a weak opioid (codeine or low-dose morphine), and finally to a strong opioid (standard-dose morphine). In Rwanda, a weak opioid such as codeine is not widely available, and we therefore substitute low-dose morphine. The WHO recommends a three-step approach to relief of pain.[1] According to the WHO, this simple method can relieve 80%–90% of cancer pain (see **FIGURE 2.2**). While designed for treatment of cancer pain, this approach is effective for pain of most causes. Patients with moderate or severe pain, or pain that is not relieved by non-opioids, can be given the standard 5-mg starting dose of oral morphine. If the pain is partially but still not adequately relieved after 60 minutes, the same dose can be repeated. If the patient has no relief after 60 minutes, a double dose should be given. This process can be repeated until adequate pain relief is achieved or until unacceptable side effects occur. In settings such as rural Rwanda, palliative care will take place primarily in the home. For this reason, we emphasize the use of oral over injectable morphine.

   A strong opioid such as morphine is first-line treatment for moderate or severe pain of any kind, including neuropathic pain. However, neuropathic pain sometimes is not relieved by opioid or non-opioid treatment. In this situation, adjuvant medications, such as amitriptyline or phenytoin, can be useful. In other situations, adjuvant medications can be used to reduce or eliminate the need for opioid therapy. For example, even severe pain caused by liver metastases sometimes can be relieved with a steroid, such as prednisolone or dexamethasone.

FIGURE 2.2 The WHO Three-Step Pain Ladder[1]



2. **Dosing intervals.** For constant or chronic pain or pain that recurs frequently, pain medications should be given around the clock at appropriate intervals, rather than as needed, to help keep pain in check. Allowing pain to rebound between doses causes unneeded suffering and can also make the pain harder to control. The analgesic effect of immediate-release oral morphine lasts 4 hours. Therefore, the drug should be given at least this frequently to control chronic pain. A double dose can be given at bedtime to help eliminate the need for a dose in the middle of the night.

3. **Opioid tolerance.** Opioid tolerance is a normal phenomenon that occurs in many patients who take an opioid for chronic pain for at least a few months or more. It means that an increase in the dose may be required over time to achieve the same analgesic effect, even when the disease remains stable. This is something that should be anticipated as a normal part of treating pain and not as a sign of psychological dependence (addiction). All patients taking pain medication should be re-evaluated regularly and their medication regimen and doses adjusted according to their needs. Patients whose disease is worsening or who develop tolerance may need progressively higher doses, while others whose disease is responding to treatment may need lower doses. However, opioid therapy should not be stopped abruptly to avoid opioid withdrawal syndrome. Rather, when opioid therapy is no longer needed, the dose should be reduced gradually by no more than 50% every 2–3 days.

4. **Route of administration.** In most cases, oral rather than intravenous or subcutaneous medications should be used, given the limited inpatient capacity and relative difficulty of providing parenteral medications in the home. In Rwanda, liquid morphine preparations will be distributed by community health workers following initial prescription by a physician. Liquid morphine is made from powder in various concentrations depending on the patient's needs. (See **APPENDIX A** for oral morphine recipes.) When patients can no longer tolerate oral medications, buccal or rectal routes may be used. Because the absorption of morphine by these routes is unpredictable, higher doses may be required.

5. **Rescue doses.** Patients taking an opioid around-the-clock for pain may have occasional breakthrough pain: a flare-up of pain despite otherwise adequate pain relief. When breakthrough pain occurs, it should be treated with an extra dose of opioid. The rescue dose should be 10% of the total 24-hour dose of opioid. For example, if a patient taking morphine 10 mg orally every 4 hours has breakthrough pain, she should be given a 6 mg rescue dose.

6. **Opioid side effects.** Most patients taking an opioid develop constipation. Therefore, a low dose of a laxative should be prescribed for most patients when opioid therapy is initiated, and the dose should be adjusted at subsequent visits based on the patient's pattern of bowel movements. Opioid-induced constipation does not diminish with time, so laxative therapy is always important for patients taking opioids. Some patients develop nausea from opioid therapy. In most cases, the nausea is mild and resolves in a few days. When it is more severe or constant, it can be treated with a low dose of haloperidol (0.5 mg orally, intravenously, or subcutaneously). Sedation is a common side effect of opioids. This, too, is usually mild and usually diminishes with time. Patients who have been in pain for some time may fall asleep when opioid therapy is started not because the drug sedates them but because they are exhausted and finally able to sleep. Respiratory depression is a rare side effect of opioid therapy when guidelines are followed, and it never occurs before sedation.

TABLE 2.3 lists the essential pain medications (based on the Rwandan formulary) that should be available at the health-center level.

TABLE 2.3 Essential Medications for Pain Relief

Symptom	Medication	Dose	Notes
Mild pain/ fever reducers (non-opiates)	Acetaminophen/ paracetamol	**Adult:** 0.5–1 gram every 4 to 6 hours. Not to exceed 4 grams in 1 day **Child:** 10-15 mg/ kg (maximum 90 mg/kg/day divided every 4–6 hours)	Use maximum 2 grams per day in patients with enlarged livers or known liver disease. Very toxic to liver in overdose.
	Ibuprofen	**Adult:** 400–800 mg every 6-8 hours (maximum dose 2.4 gm/day) **Child:** 10 mg/kg every 6–8 hours	Particularly effective in bone pain. Anti-inflammatory at higher doses. Can cause digestive upset and gastrointestinal bleeding. Do not use in renal failure. Decrease doses in patients with severe liver failure. Prolonged prescription requires cimetidine or omeprazole for gastrointestinal prophylaxis.
	Diclofenac	**Adult:** 25–75 mg every 12 hours	Same as ibuprofen, but less expensive for long-term use, with simpler dosing.
Moderate to severe pain	Morphine, liquid preparation	**Adult:** 2.5–10 mg every 4 hours. May give double dose at bedtime. No maximum dose. Titrate to patient comfort. **Child:** 0.15 mg/ kg–0.3 mg/kg every 4 hours. Titrate as with adults.	Dose increases may be limited by oversedation. Should decrease the dose or increase the dosing interval in case of any renal failure. Constipation is a common problem and all patients should be placed on a bowel regimen prophylactically (see **TABLE 2.5**).
Neuropathic pain (burning pains or shooting)	Amitriptyline	**Adult:** 10–25 mg by mouth daily. **Child:** 0.1 mg/kg once a day at bedtime. Increase as needed by 0.2–0.4 mg/kg every 2–3 days to a maximum of 2mg/kg/day	Dose should be titrated upward every week to effect. May take weeks to work. Maximum dose in adults is 100 mg per day. Side effects include initial drowsiness, postural hypotension, dry mouth, mild tachycardia, constipation. Life-threatening cardiac toxicity with overdose.
	Phenytoin	**Adult:** 100 mg twice per day initially, increase up to 400 mg twice per day if needed **Child:** 2.5–5 mg/ kg twice per day (maximum 200 mg twice per day)	Can use instead of, or in addition to, amitriptyline if neuropathic pain persists. Avoid if on anti-retrovirals due to drug interactions.

Symptom	Medication	Dose	Notes
Muscle spasms	Diazepam	**Adult:** 2.5–10 mg by mouth 2 to 3 times per day **Child:** 0.05 mg/kg–0.1 mg/kg 3 to 4 times per day (maximum 0.8 mg/kg/day)	Drowsiness, ataxia.
Pain from swelling, inflammation, or neuropathy	Prednisolone	**Adult:** 20–80 mg by mouth daily **Child:** 1 mg/kg x 1–2x/day by mouth	May also improve nausea, fatigue, and appetite. Particularly helpful in the case of malignant lesions causing localized swelling in the muscle or bone. The dose should be decreased gradually over a period of 2–3 weeks and then stopped to avoid side effects.

2.2.4 Dyspnea

Many types of chronic disease can result in severe dyspnea. Heart failure and chronic respiratory disease can cause dyspnea even in early stages. Treatment protocols outlined in the following chapters will help to relieve this symptom. Patients with dyspnea due to advanced, untreatable cancers and those dying of respiratory compromise from any cause should be treated with an opioid such as morphine if other treatments are not effective. Morphine is very effective at relieving dyspnea. Dosage is the same as for pain (see **SECTION 2.2.3**). At the end of life, some patients develop secretions in the upper airway and throat. The sound that these secretions make when air passes through them can be disturbing for family members even when the patient is not short of breath. Counseling by a community health worker in this situation can be helpful. Hyoscine butylbromide, an anti-cholinergic medication, can also help dry secretions if needed. The typical dose for adults is 20 mg every 2–4 hours around the clock, or as needed. The medicine can be given either orally or rectally, as described below for anti-nausea medications.

2.2.5 Nausea/Vomiting

Nausea and vomiting occur with many chronic diseases, either as a result of the disease process itself or as a side effect of medications. Nausea may have many causes. For instance, in heart, liver and renal failure, the gut walls may become edematous and function poorly, a condition that leads to nausea and vomiting. Nausea-producing substances that are either taken into the body (such as medications or food toxins) or produced by the body (in liver or renal failure, for example) stimulate certain areas of the brain that control nausea and vomiting. **TABLE 2.4** indicates the appropriate therapy for nausea depending on the cause. When patients cannot tolerate oral medication, tablets may be ground up and mixed with water for rectal insertion via a syringe without a needle.

Haloperidol and promethazine occasionally may cause a dystonic reaction, characterized by muscle spasms. This is uncomfortable, but not dangerous, and should be treated with diphenhydramine.

TABLE 2.4 Essential Medications for Control of Nausea/Vomiting

Cause of nausea	Therapy
Liver failure, renal failure, metabolic derangement, drug side effect, or bacterial infection (nausea due to a toxin or inflammatory mediator)	**Haloperidol** **Adult:** 0.5–1 mg 2–4 times per day given orally, IV, or SC, around the clock or as needed **Child (≤ 40 kg):** 0.025–0.05 mg/kg/day in 2–3 divided doses. Increase by 0.25–0.5 mg/day every 5–7 days as needed to maximum dose 0.15 mg/kg/day
	Promethazine **Adult:** 12.5–25 mg every 4 hours orally, IV, IM, or by rectum **Child (≤ 40 kg):** 0.25–1 mg/kg 4 times a day orally, IV, IM, or by rectum. Maximum dose: 25 mg per dose
	Dexamethasone **Adult:** 8–20 mg once a day in the morning or 4–10 mg 2 times per day IV or IM, around the clock or as needed **Child (≤ 40 kg):** 0.5–1 mg/kg 2 times per day IV or SC around the clock or as needed. Maximum dose: 10 mg 2 times per day
Increased intracranial pressure, bowel obstruction, or distension of liver or of hollow viscus due to neoplasm	**Dexamethasone** **Adult:** 4–10 mg 2 times per day IV or IM, around the clock or as needed **Child (≤ 40 kg):** 0.5–1 mg/kg 2 times per day IV or SC around the clock or as needed. Maximum dose: 10 mg 2 times per day
Anxiety	**Diazepam** **Adult:** 2.5–10 mg 3 times per day, orally, IV, or SC, around the clock or as needed **Child (≤ 40 kg):** 0.05–0.1 mg/kg/day divided 3–4 times per day (maximum 0.8 mg/kg/day)
Gastroparesis	**Metoclopramide** **Adult:** 10 mg, 4 times per day, orally, IV, or SC, around the clock or as needed. **Child:** 0.1-0.2 mg/kg/dose 4 times per day, orally, IV or SC, around the clock or as needed
Stimulation of vestibular apparatus	**Chlorpheniramine** **Adult:** 4 mg orally every 4 hours, around the clock or as needed **Child (≤ 40 kg):** 1–2 mg by mouth every 4–6 hours. Maximum dose: 6 mg/day for 2–5 yo, 12 mg/day for 6–11 yo, around the clock or as needed
	Promethazine **Adult:** 12.5–25 mg every 4 hours orally, IV, IM, or by rectum **Child:** 0.25–1 mg/kg 4 times a day orally, IV, IM, or by rectum. Maximum dose: 25 mg
Adjuvants for nausea/vomiting of any cause	**Chlorpheniramine** **Adult:** 4 mg orally every 4 hours, around the clock or as needed **Child (≤ 40 kg):** 1–2 mg by mouth every 4–6 hours. Maximum dose: 6 mg/day for 2–5 yo, 12 mg/day for 6–11 yo, around the clock or as needed

2.2.6 Constipation

Constipation frequently afflicts patients with chronic illness, either as a side effect of medications or due to the disease itself. In addition, chronically ill patients may not be very mobile or may be unable to tolerate fibrous diets, further slowing intestinal motility.

All patients with constipation should be assessed for fecal impaction with a digital rectal exam and disimpacted manually as needed. All patients should be encouraged to take fibrous foods and fluids, as tolerated. Laxatives and enemas may also be used to ease constipation (see **TABLE 2.5**). The most common types of laxatives are stimulants (bisacodyl), osmotic agents (lactulose), and lubricants (glycerine). In patients with constipation due primarily to opioid therapy, a stimulant laxative is first-line therapy. Osmotic laxatives should be used only in patients who are well hydrated. In severe cases of opioid-induced constipation, oral naloxone can be used to reverse the opioid effect on the gut.

TABLE 2.5 Essential Therapies for Treating Constipation

Treatment	Dose
Glycerin suppository	**Adult:** 4 gm suppository per rectum daily **Child (≤ 40 kg):** 2 gm suppository per rectum daily
Lactulose syrup	**Adult:** 15–45 ml 2–3 times per day orally, maintain 30–90 ml/day **Child (≤ 40 kg):** 7.5 ml 1 time per day orally
Bisacodyl	**Adult:** 10 mg once or twice daily, orally or per rectum **Child (≤ 40 kg):** 0.3 mg/kg once daily by mouth. Maximum dose: 10 mg. Can also be given per rectum
Naloxone	**Adult:** 1–2 mg every 8 hours. Should only be given orally for this indication

Patients with intermittent bowel obstruction due to a malignancy may benefit from steroid therapy (see prednisolone dosing in **TABLE 2.3**).

2.2.7 Diarrhea

Many chronic illnesses can lead to diarrhea. For instance, cancer treatments that can cause diarrhea include some chemotherapeutic drugs, or radiation. Patients with diarrhea who take a diuretic medication should be seen by a clinician for adjustment of therapy to avoid dangerous volume depletion. Patients with chronic illness are also more susceptible to infectious causes of diarrhea. In the case of accompanying fever or bloody stool, infectious causes should be considered as a possibility and treated appropriately. Conversely, antibiotics also can cause diarrhea by killing normal bowel flora.

All patients with severe diarrhea should have oral replacement of fluids and electrolytes, if possible and appropriate. When a patient taking a

laxative develops diarrhea, the laxative should be discontinued until the diarrhea stops.

TABLE 2.6 outlines the evaluation and treatment of diarrhea not obviously due to infection. Narcotics and anticholinergic medications such as hyoscine butylbromide can help reduce diarrhea if loperamide is not available.

TABLE 2.6 Symptomatic Management of Diarrhea

Treatment	Dose
Loperamide	**Adult:** 4 mg orally initially, then 2 mg orally after every loose stool, up to a maximum of 16 mg per day **Child (weight 13–20 kg):** 1 mg orally 3 times per day **Child (weight 21–30 kg):** 2 mg orally up to 3 times per day
Morphine, liquid preparation (low dose)	**Adult:** 2.5 mg every 8 hours. May give orally, buccally, or rectally **Child (≤ 40kg):** 0.15 mg/kg, up to 2.5 mg every 4 hours. Administer as with adults
Hyoscine butylbromide	**Adults:** 10–20 mg every 6 hours orally or rectally

2.2.8 Delirium/Agitation

Patients with terminal illness may become delirious with or without agitation. Delirium and agitation are associated with significant morbidity and mortality and are distressing to both the patient and the family. Common causes of delirium include psychoactive medications (especially benzodiazepines), renal or liver failure, hypoxia or hypercapnia, metabolic derangements such as hypercalcemia, or central nervous system disorders such as infection, bleeding, or tumor. Sometimes there is an underlying permanent dementia that must be distinguished from reversible delirium, and often delirium has multiple causes.

Treatment of delirium includes trying to orient the patient, attempting to maintain normal sleep-wake schedules, and avoiding benzodiazepines. Patients may also be treated with haloperidol at a dose of 0.5–5 mg 2 to 4 times per day orally. It may be given more frequently for severe symptoms. Chlorpromazine, a more sedating medication, also can be used at 10–50 mg 2 or 3 times per day orally. Heavily sedating the patient is not recommended, except in extreme circumstances when the patient's safety is at risk.

2.2.9 Pruritus and Pressure Ulcers

Pruritus or itching is a common but often overlooked side effect of chronic illness that can cause severe distress. Renal failure often causes pruritus. Any patient with chronic illness is at risk for cholestasis, which also can cause itching. Opiates can also cause pruritus.

Treatment depends on the cause. Any allergenic medication or substance should be identified and removed. If morphine that is needed to treat pain or dyspnea appears to be the cause of pruritus and no other strong opioid is available, an antihistamine such as chlorpheniramine may provide relief. The lowest effective dose should be used due to this medication's sedating effect. Pruritus in the setting of renal failure is often due to dry skin and can be relieved by emollient lotions. See **TABLE 2.7** for treatment details.

Skin care of chronically ill, bedridden, malnourished, or incontinent patients is essential. Patients can quickly develop pressure ulcers, skin tears, and superficial fungal infections. The patient should be kept as clean and dry as possible. Intact skin can be cleansed with an antibacterial agent such as povidine-iodine. Open wounds should be cleansed gently with saline. A wet or bleeding wound can be packed with povidine-iodine gauze. Dry wounds should be packed and dressed with gauze or cotton coated with petroleum jelly. If the wound is malodorous, metronidazole powder should be sprinkled on the wound prior to applying the dressing. Metronidazole powder may be obtained either by opening metronidazole capsules, or by crushing the tablets.

TABLE 2.7 Management of Chronic Pruritus and Skin Care

Condition	Treatment
Pruritus due to dry skin, renal failure	Emollient lotion such as calamine
	Chlorpheniramine **Adult:** 4 mg orally every 4 hours, around the clock or as needed **Child (≤ 40 kg):** 1–2 mg orally every 4 hours, around the clock or as needed
Contact dermatitis (e.g., from tape used in hospitals)	Remove allergenic substance High-potency topical steroid such as 0.05% betamethasone valerate
Scabies	Permethrin lotion applied from head (avoid face) to toes. Leave lotion on for 8–14 hours, then wash off. The usual adult dose is 20–30 grams. Repeat in 1 week. Wash all clothes and bedding and dry in the sun. Do not use for babies less than 2 months old
Cholestasis	**Adult:** Prednisolone 10 mg per day. Cimetidine 400 mg twice per day.
Pruritus due to opioids	**Chlorpheniramine** **Adult:** 4 mg orally every 4 hours, around the clock or as needed **Child (≤ 40 kg):** 1–2 mg orally every 4 hours, around the clock or as needed
Foul odor from wounds	Keep wound clean. Crush metronidazole tables and sprinkle onto wound daily

2.2.10 Giving Bad News

Care should be taken whenever giving bad news to minimize emotional distress for the patient and family. The following is a list of general guidelines for giving bad news, however each cultural setting may require different techniques.

1. Determine in advance whom the patient would like to receive medical information and the most culturally appropriate way to give bad news.
2. Suggest that support persons such as family members or friends be present when bad news will be discussed.
3. Take the time to sit down.
4. First explore the patient's or family's understanding of the disease and gently correct misconceptions.
5. Pause frequently to give the patient or family a chance to absorb the news and ask questions.
6. Be prepared for strong reactions such as anger or grief.
7. Offer to see the patient or family soon again to answer questions and provide emotional support.

2.2.11 Psychosocial and Spiritual Issues

Patients with chronic diseases often experience significant social, financial, and spiritual distress. Often, this is the most difficult aspect of their disease. Community health workers can help provide support to these patients. They can also identify those in need of more intensive psychological, social work, or spiritual support. In Rwanda, almost all district hospitals have a neuropsychiatric health nurse who can see patients with symptoms of depression or anxiety. There is also a social work team that can make home visits and assess needs for housing, food, and educational support. In some cases, patient associations may serve as a source of support to patients. In Rwanda, patient associations have served as a platform for income-generating activities and have also provided a community for patients living with HIV.

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