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Palliative Care

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BASIC PALLIATIVE CARE

Gynecological cancers are most distressing to the patient and the family. This is so all over the world, but in resource-poor countries, it may be a death sentence with a painful journey from diagnosis to death itself. The economy of the country in which we live at the time of diagnosis, has a huge effect on our access to treatment. In our experience, African women suffer the most and as they are the main carer in the family, the children suffer with them during the illness and later. It is not just physical pain, but also the traditional role of women that is now threatened by a death sentence and an illness attacking the very center of her womanhood. The psychological fears, as well as physical suffering, from misunderstandings with the husband can make life a living hell for her.

All these problems need to be taken into account and palliative care seeks to do this. But the person who is bringing palliative care needs to be knowledgeable, not only of pain and symptom control, but also of the local cultural attitudes towards women and their role in the family. Spirituality and religion, is a comfort and most women would want their carer to listen to their problems and to pray with them. This can be done comfortably within the home. However, many gynecologists and oncologists insist on providing invasive therapy, causing pain and distress, up to the last (Box 1). We need to be ethical in our approach to the terminally ill patient taking into account the prognosis for life or for time left. If time was short, then most patients would prefer to spend this with their family, not in hospital suffering with painful treatments offering them false hope. It is heart breaking to see how many women are subjected to

fruitless suffering due to the false beliefs of consultants that they can extend life. Palliative medicine improves the quality of life and may prolong the overall survival¹.

Box 1 A case study

Mary was admitted to a gynecological ward in Nigeria. She had stage III cancer of the cervix extending throughout the pelvis and blocking off her right ureter so that she had hydronephrosis. There was no radiotherapy in the hospital. The gynecologist insisted on doing a cystoscopy with a view to passing a stent into the right ureter costing US\$40. To get this money the family would have to sell property. After which there wouldn't be any money for her care and the medications she needed to control her pain. In Nigeria patients pay for all their palliative care medications and if they do not have money they are turned away in pain. Luckily the family was unable to raise enough and she went home where the palliative care home care team managed her and her pain was controlled until she died.

Thus if you are going to be able to address the many faceted areas of palliative care, it is more important to be a special person than to be a specialist!! We need to be willing to give time to our patient and even time away from the patients when you learn what is needed in your part of this world.

In this chapter we will refer to our own experiences in Uganda and other African countries. However every country, every tribe, every family, is different.

What is palliative care?

The World Health Organization (WHO) defines palliative care as²:

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

Thus we can translate this into our daily practice as:

- We are aiming at the best possible quality of life for our patient.
- Palliative care means that impeccable assessment leads to early identification and treatment of problems, physical, psychosocial, cultural and spiritual.
- Our care and approach indicates that we affirm life (while being prepared to tell the truth) and I myself regard death as a normal process (cure is neither success nor dying a failure).
- Acknowledge that while not curing my patient, bringing palliative care often extends life.

Women’s cancers are at the top of the list of cancers identified in resource-poor settings. Cancer of the cervix is number 1 in Uganda, while cancer of the breast is number 1 in Nigeria. In most countries in Africa, these are similar in incidence and they are the main cancers we deal with. Cancer of the ovary is less common but brings a poor prognosis and terrible suffering. In sub-Saharan Africa in particular, the suffering of cancer in women may be compounded by HIV/AIDS.

The reality where resources are poor, is that cancer is often not a priority in healthcare because infections are the major top ten causes of death. Early detection and methods for early detection are in their infancy, such as cervical screening. Most women present late if at all. Remembering that in Uganda 57% and in Ethiopia 85% of sick people never see a health worker, we can see that many are lying in the villages waiting for death in terrible

pain. Chemotherapy and radiotherapy are often only available to the very rich and sometimes not at all.

Principles of palliative care

1. The patient is the center of care. The comfort and peace of the patient is our priority. The patient is our guest and will take part in decision-making with the physician and the team up to her death. The care of the patient is holistic, including addressing all of the needs of patient and family. The palliative care physician may have to interact with oncologists, radiotherapists, surgeons and others, ensuring that investigations and management decisions are made with the comfort of the patient always in mind. Some investigations and treatments may have to be avoided if they worsen the quality of life, or if the patient decides she prefers to be without further treatments. However, in less-resourced settings, other options for oncology, radiotherapy and even surgery are usually not available.
2. Wherever possible the physician works with a team. In less-resourced settings a nurse is often the leader of the team. The team is non-bureaucratic and cares for each other while sharing information with confidentiality, for the good of the patient and family.
3. Teaching others is essential in resource-limited situations where palliative care is new. It is through those we train that palliative care will reach more in need in countries where the majority of cancer patients die in pain and misery without dignity.
4. We recognize that there is a need for all of us to meet the needs of our patients and families. We therefore network with other organizations, and respect them without being in rivalry situations. Recent research into pain and symptom control has brought palliative care to a specialty level under medicine. We need to be knowledgeable in order to assist our patients with affordable medications, and be available to be a friend, counselor and spiritual supporter.

Pain

Physical pain

Physical pain can be soul destroying not only to the patient but also to the family. Children who have

witnessed the suffering of a parent have memories affecting them all their lives. Families may ask for admission or place the patient in an outhouse far from the family, so that the family can catch some sleep without hearing their cries.

Thus, diagnosing physical pain, and treating and removing such pain opens the door to the other facets of palliative care. While in severe pain, neither the patient nor the family can make plans, say their farewells or come to peace with their families or their religion. Thus, understanding pain and managing it is essential to palliative care. Relieving pain opens the door to the holistic diagnosis and management of other aspects.

Dame Cicely Saunders³, founder of the Modern Hospice Movement, spoke of 'Total Pain'. She defined this concept of 'total pain' as the suffering that encompasses all of a person's physical, psychological, social, spiritual and practical struggles (Figure 1). All these must be addressed.

Some basics on pain and treatment of pain in resource-poor settings

'Pain is what the patient says hurts'. Other scientific definitions cannot get across the importance of this clinical concept. All pain needs our attention and impeccable assessment.

Somatic pain is felt when the nerve fibers from the site of the injury to the brain are intact. Neuropathic pain indicates damage to a nerve and interruption or alteration of transmission (Figure 2). Pain may be somatic: i.e. the nerve fibers are intact so what is felt is a result of damage to an area which can be recognized for what and where it is. Peripheral pain may be from inflammation on the skin or the joints. Visceral pain is pain arising from

damage to an organ, which is stretched or inflamed. The pain is difficult to locate and may be indicated in a wider area than the injury.

Somatic pain: peripheral and visceral somatic pain usually respond to the analgesic ladder (Figure 3). It is due to the release of prostaglandins at the nerve endings. Non-steroidal anti-inflammatory drugs (NSAIDs) and corticosteroids act by neutralizing the prostaglandins and are often referred to as anti-prostaglandins.

Medications from each step are usually available even with limited resources if affordable. However the resources of the patient and family now come into play. Few countries have medications affordable to all or free to all.

In cancer, analgesics must be given so that the pain never returns. This means that another dose is

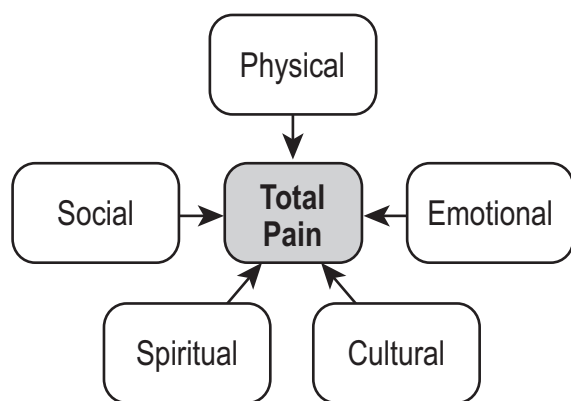


Figure 1 The concept of 'total pain'

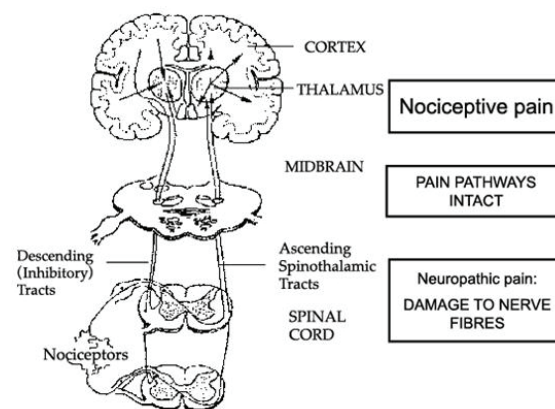


Figure 2 Somatic and neuropathic pain pathways

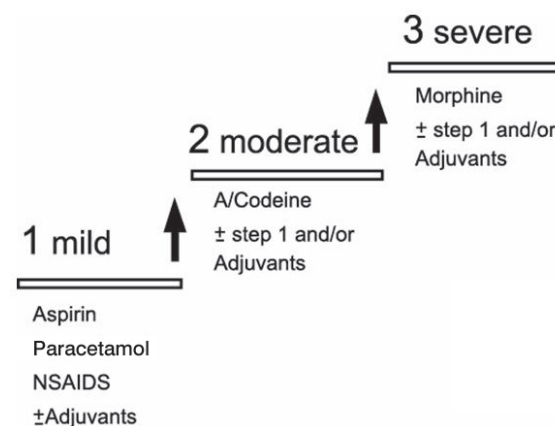


Figure 3 The analgesic ladder. Adapted from EPECTM with permission

given at the time relating to the half-life of the substance (Figures 4 and 5) but, if this is not working, the timing may have to be adjusted. The pain must not be allowed to return. The aim of pain control is to have a patient who is alert, able to work, think and enjoy life without side-effects and without fear of the pain returning. Figure 6 shows the half-life of selected analgesic drugs.

Figure 7 shows diagrammatically how important it is to administer analgesic drugs by the clock in a dose that does not cause drowsiness and does not allow the pain to return. How we give the treatment is very important. We must take into account the patient's responsibility and our own, to observe individual needs, when taking her own medicines.

The analgesic ladder

The analgesic ladder (Figure 3) was first recommended by WHO in 1986. It is important to follow up pain and re-assess it until from a high score (on 0–5) the pain is at 0. Various techniques are used to measure pain improvement and the commonest one is shown in Figure 8. Use a diagram as shown in Figure 9.

Analgesics for somatic pain

Step 1 NSAIDs at the peripheral nerve endings by blocking prostaglandin release. Paracetamol is the safest and is effective in many patients.

Steps 2 and 3 These are are opioids. Step 2 is usually available as codeine or dihydrocodeine. Both are expensive and have a ceiling. For cancer patients, most are now leaving out this step and going from

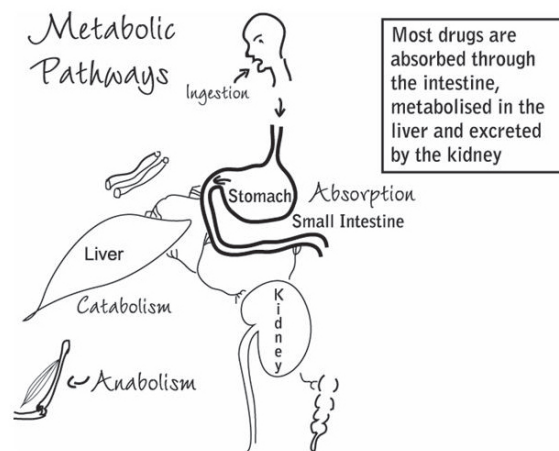


Figure 4 Metabolic pathways

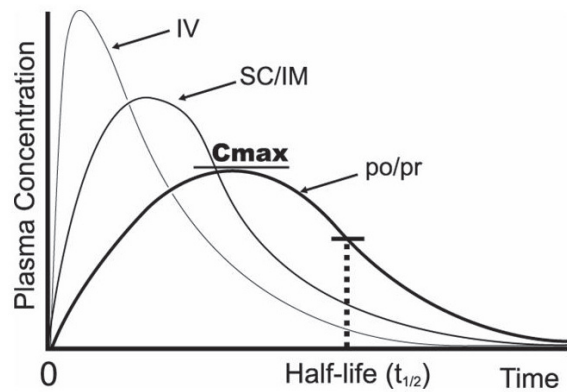


Figure 5 Half-life of drugs according to method of administration. Adapted from EPEC™ with permission

- STEP 1
 - Aspirin 4 hours
 - Paracetamol 4 hours
 - Ibuprofen 4 hours
 - Diclofenac 8 hours
- STEP 2
 - Codeine 4 hours
- STEP 3
 - Morphine solution 4 hours
 - MST® 12 hours

Figure 6 Half-life of selected analgesic drugs

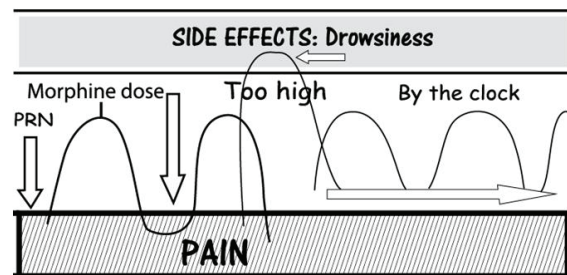


Figure 7 Importance of administering drugs by the clock

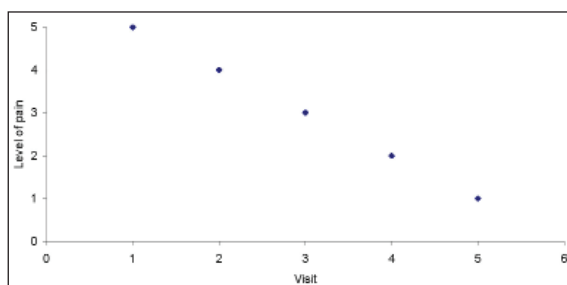


Figure 8 A visual analog scale of 0–5 is used to identify pain, with 0 ‘I do not have any pain’ to 5 ‘My pain could not be worse’. The fingers of the hand can also be used to indicate 0–5. The pain should be less at each visit

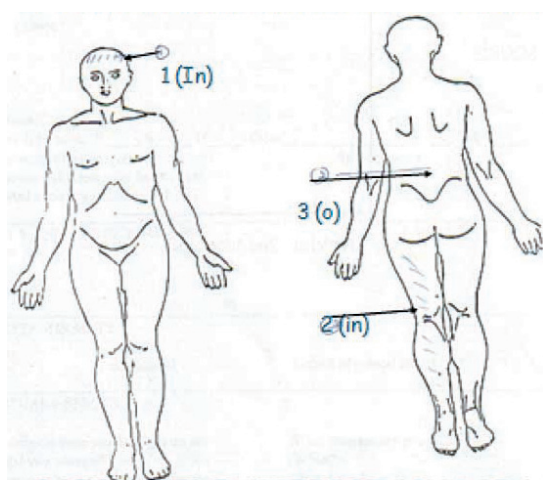


Figure 9 A pain assessment chart. The patient identifies each pain and it is numbered by the health worker

step 1 to step 3, using a weak solution of morphine in low dose.

Step 3 Affordable oral morphine solution needs to be available in the home for the control of severe cancer pain and AIDS-related pain such as headache from cryptococcal meningitis. The formula for oral morphine is given in the book ‘*Pain and Symptom Control in Uganda and other African Countries*’ available from the Hospice Uganda website: <http://www.hospiceafrica.or.ug/index.php/>

Oral morphine suitable for use in the home

This is now available in some African countries using a simple formula^{4,5}. It is still the price of a loaf of bread in some countries and at most US\$1–1.5 for 500 mg. However, additional costs are making it

five to six times more expensive in some countries and it is up to each country to have a watch-dog on prices, if those in need are to be relieved of pain.

It is very simple to make as it is a matter of mixing the morphine with water, a dye and a preservative. Thus it can be made in a simple pharmacy if the ingredients are available, as well as an accurate scale to weigh the morphine powder and clean filtered water. In Uganda we have used recycled water bottles and this has proved to be safe and affordable. Oral morphine is commenced according to severity of the pain and the condition of the patients at 2.5–5 mg 4-hourly and a double dose at bedtime. If a patient is in severe pain, an initial dose of 10–20 mg may be given. This will usually act within 20 min by mouth.

Morphine is anticholinergic and the most frequent side-effect is constipation. This is avoided by giving a laxative with the initial dose and instructing the patients to increase it if the effect is insufficient. Once the bowel function is normal, the effective regular dose is given. A laxative is necessary and imperative to be given alongside morphine unless the patient is suffering from diarrhea. Bisacodyl is available and affordable in most countries and works. Pawpaw seeds, dried and crushed are a cheaper alternative: 1–5 teaspoons at night will keep the patient from the discomfort of acute constipation.

Morphine is titrated against the pain and does not have a ceiling. Doses of 15–200 mg per day in divided doses have been used, with a mean dose, in our experience for the average patient, being 30 mg per day. However in the West, doses of up to 5000 mg per day have been recorded. Slow-release morphine tablets are available but are very expensive and are usually imported specially for specific patients.

Neuropathic pain

The mainstay of treatment of neuropathic pain is antidepressants, of which the most affordable and available one is amitriptyline. This is given starting with the smallest dose available, i.e. 10–12.5 mg once daily at night. If there is no relief after 3 days it can be slowly increased at 3-day intervals. If the pain is not controlled by 50 mg daily, the patient will probably not respond.

The alternative, traditionally given for the ‘shooting’ element of pain is an anticonvulsant. Carbamazepine is classically recommended in

medical textbooks but it has side-effects and the patient should ideally, initially, have their white blood cell (WBC) count measured regularly, and it is not always affordable and available. Phenytoin is available, affordable in most resource-limited countries and it works. A dose of 100mg three times a day (t.d.s.) is usually sufficient.

For herpes zoster pain, an AIDS-defining disease, and also common in other immunosuppressed patients, try topical milk from the broken off branch of a frangipani tree. It is applied topically to the site of the lesion, three times a day.

It must be remembered that morphine also has some effect on neuropathic pain and if commencing this for other pain, it is recommended to wait to see if it works for the neuropathic pain component as well before introducing antidepressants or anticonvulsants.

Remember that most patients with gynecological cancers have multiple types of pain.

PAIN AND SYMPTOMS OCCURRING IN GYNECOLOGICAL CANCER

Cancer of the cervix

This is the commonest cancer in Uganda and some other African countries. For medical information on cervical cancer, please see Chapter 26. Cervical cancer occurs at ages from 25 to 70 years but can occur in younger women. Commonest age groups are between 30 and 50 years.

In countries where many women never see a health worker, the community volunteer working with hospice or support organizations, may be the first one to recognize the symptoms. The initial symptom is abnormal bleeding but most women will attend the traditional healer for this. They usually present to a health worker at stage III or IV except in those countries where cervical screening is encouraged and is free, i.e. women are now presenting earlier in under-resourced countries if they are attending cervical screening.

The role of the palliative care clinician: pain control

Take a thorough history of the pain, and plot on a pain chart using the tools described in the section on pain (Figures 8 and 9). For somatic pain: use the analgesic ladder. For neuropathic pain not responding to other medication: use an antidepressant or anticonvulsant as above.

Common types of pain in cervical cancer

- Cramp-like pain in the lower abdomen: described as cramps comparable to period pains or 'like having a baby that never comes!' These are often due to a mass which is stretching the cervix. It usually responds to the analgesic ladder but if possible should be debulked by radiotherapy.
- Pain in the back radiating to the anterior and over a large area of the back. This is due to the involvement of the nerves of the cauda equina. This pain may also pass down the leg(s). This may need additional medication for neuropathic pain.
- Dysuria due to bladder involvement.
- Distal pain due to metastasis. May be due to stretching of the liver capsule or pain in the bones due to metastatic areas involving the periosteum.

Symptoms

- *Bleeding*: this may be heavy depending on the stage of the disease and indeed some women bleed to death if not given a blood transfusion.
- *Discharge with a foul smell*: this is the smell of rotting flesh invaded by anaerobic organisms and requires the application of metronidazole powder (crushed tablets), on the area. Tablets of metronidazole can be inserted into the vagina if pessaries are not available.
- *Urinary incontinence due to vesico-vaginal fistula (VVF)*: this may be due to direct tumor invasion or due to radiotherapy which is really contraindicated if there are urinary symptoms or invasion into the bladder by the tumor. This can be managed with locally made plastic pants, gusseted at each side of the crotch to prevent leaking. Soft washable cotton can be put inside and this allows the woman to continue with her domestic or other routine without the shame of leaking urine and smell. But a routine of changing regularly needs to be adopted.

Ovarian cancer

'The silent killer' is known to present late and even later in resource-poor countries. When first seen, the patient may be wasted with a distended abdomen (due to masses and/or ascites). Pain needs to be assessed and classified from the description given by the patient into somatic, neuropathic or both. Intestinal obstruction is common and requires a

high index of suspicion from the health worker. Management is largely symptomatic as follows (the same is also applicable in intestinal cancer).

Management

The presentation (depends on the level of the obstruction) is often *nausea and vomiting*; if the ileum or above is involved, this occurs early, but lower down symptoms of obstruction may take some time to show. Drip and suck can be offered as a choice. In our experience however it is the nausea that is distressing to the patient, not the vomiting. Nausea is managed well with haloperidol 1 mg daily rectally or in the buccal mucosa. If vomiting is very distressing, a nasogastric tube may bring relief.

Control *pain* with rectal (12-hourly using slow-release tablets if available) or oral morphine into the buccal mucosa with a concentrated solution 4-hourly and a double dose at night. Remember anything that can be given orally can be given and absorbed rectally. Thus other medications can be given per rectum (PR). Hyoscine may be required with morphine for severe colic.

Note: palliative care teams in some richer countries prefer to give medications through subcutaneous routes (SC) via the syringe driver when oral therapy is not possible. In some countries this is not acceptable in the home where most wish to be at the end of life. Thus, it is important to be aware of the cultural aspects of caring. Remember once SC is in place the patient needs to be visited more frequently and this is not always possible. Avoid surgery as often there are multiple obstructions and surgery can lead to gross postoperative discomfort and weakness.

When *ascites* is one of the leading symptoms you can aspirate ascites under ultrasound guidance, if available: look with a transabdominal ultrasound probe for a place in the abdomen where no bowels are near the abdominal wall. Mark this place with a pen. Disinfect the abdomen, insert an IV cannula in the abdominal cavity and remove the needle once you aspirate the ascites, leaving the cannula inside. Connect the cannula via an IV giving set to a basin and allow approximately 2 liters to drain in this basin. Then remove the cannula and apply a sterile gauze. The advantage for the patient is immediate relief of the symptoms associated to distention. Disadvantages are that she will lose a lot of protein via

the ascites, and you may damage the bowel when you do not insert the cannula properly and this can lead to peritonitis.

Honesty with the patient and the family is important at this stage. Concentration on the need for quality of life and avoiding anything which interferes with this in the light of the prognosis, needs to be made clear to all. Holistic care with good listeners and meeting needs of all is essential. Spiritual support from the team is very much appreciated.

Ovarian cancer may affect young women with young families as well; it is necessary to give as much emotional support as possible, listening to the many problems and trying to ensure that the team can assist with the very practical worries of a mother for her children and their welfare, including finding sponsors for their school fees after their mother has gone.

Breast cancer

This can present in many ways but often the patient with breast cancer does not present at all but may be found in the village in severe pain (Figure 10). Others just die, isolated by severe pain with terrible smells from their fungating lesions. The breast is a life-giving organ, and a debilitating breast disease is often considered the worst fate for a woman. The fear of mastectomy and of losing her attraction to a man is a factor delaying reporting to a health facility. Many attend a traditional healer for a long time, suffering with applied poultices and incisions of the tumor before seeking care from biomedicine. The main problems are shown in Table 1.



Figure 10 Mary was found lying in her bed in the village; she had never attended a health worker and was in severe physical and psychological pain

Table 1 Main problems associated with breast cancer

<i>Symptom</i>	<i>Cause</i>	<i>Management</i>
Pain: in breast in wound	Primary cancer	Step 1 analgesics
Pain in other sites: bone, liver, brain	Metastasis	Paracetamol, NSAIDS and/or morphine, NSAIDS or low-dose steroids, high-dose steroids to relieve pressure plus morphine
Bleeding wound	Vascular invasion	Radiotherapy
Smelly wound	Anaerobic organisms in dead tissue	Apply crushed metronidazole tablets to site after cleansing b.d.
Paraplegia	Bony metastasis in lumbar spine	Immediate high-dose dexamethasone. Consider radiotherapy if available. Management of paraplegia, turning, bladder and bowel care
Psychosocial pain	Culture etc.	Counseling
Spiritual pain	Beliefs and guilt	Listening and supporting with family or with requested spiritual guide

NSAIDS, non-steroidal anti-inflammatory drugs.

HIV/AIDS

The scourge of sexually transmitted HIV has brought much suffering to many resource-poor settings where the majority of sufferers are found. Women, in particular, have suffered, not only from the physical pain and symptoms but from misunderstandings, rejection and stigmatization, as well as seeing children die before them infected by the same virus via mother-to-child-transmission. Women with HIV have special gynecological problems and needs. See Chapter 18 for a more detailed description of this subject. HIV has doubled the incidence of cancers in Africa and women are more affected by Kaposi's sarcoma and cancer of the cervix.

However, HIV is not the same disease as it was 20 years ago when it was visible at any gathering with many having the dreaded 'slim' disease. The advent of affordable antiretroviral therapies (ARVs), mainly supplied by donors, has made a great difference. Many now die of something else if they can access treatment. It is estimated that, on average, 60% of those in need of ARVs access continuous treatment in African countries. The other 40% are mainly living in rural areas with poor access to modern medicine. These still die of opportunistic infections with severe suffering and stigmatization. Most of them will not reach care unless there are community volunteer workers in each village, specially trained to be vigilant, who report those suffering to the palliative care team. This has worked well in Uganda.

Those who are feeling good and receiving ARVs are supported by 'support organizations'. However, palliative care requires skills and knowledge of the management of the opportunistic infection and control of pain and symptoms (Table 2). Many patients will come from the ARV clinics with side-effects of ARVs. The palliative care team will mainly be dealing with the very ill patients in clinical stage IV of HIV. For the general background on HIV we refer to other publications. In this chapter we will highlight a few palliative care issues of HIV/AIDS.

Immune reconstitution syndrome

Immune reconstitution inflammatory syndrome (IRIS) is a condition of increasing importance and seen with increasing frequency as more patients access highly active antiretroviral therapy (HAART). The effect of the antiretroviral drugs allows suppression of the virus and recovery of the immune system. In patients with underlying opportunistic infections such as tuberculosis, cryptococcal meningitis or toxoplasmosis, the immune system suddenly recovers enough to start fighting these underlying, previously hidden infections and mounts an immune response against them. This response can be quite violent and occurs classically within 3–8 weeks (but may be delayed for months) of a patient starting ART. Patients become acutely unwell, presenting with severe symptoms of infections, e.g. rapidly enlarging lymph nodes due to tuberculosis,

Table 2 Management of commoner symptoms in HIV/AIDS

<i>Symptom</i>	<i>First line</i>	<i>Second line</i>	<i>Other</i>
Diarrhea	Fluid replacement oral	IV fluids, morphine 2.5 ml 4 hourly	Oral rehydration fluid (ORS)
Dysphagia + weight loss	Antifungals: nystatin, fluconazole. Dexamethasone 16 mg IV once then oral reducing by 2 mg daily	Clotrimazole: pessaries by mouth (call them lozenges) for resistant fungal infection	Can raise the dead to life!
Herpes simplex ulcers	Mouth or genital area use herpetic solution (HAU)	Herpetic solution (made up from ingredients in next column as a solution and painted onto affected area twice a day)	Aciclovir 200 mg tablet, 2, metronidazole 200 mg 2 tablets + nystatin oral suspensions 100,000 u/ml 30 ml
Skin infections: usually multiple causes	Early: 0.1% steroid cream may help after 0.5% rinse b.d.	Later just use the 0.5% rinse after showering twice a day	Cause is multiple infections
Scabies	Benzyl benzoate solution apply for 3 days after bath	Lindane, malathion	
Fungal infections	Whitfield's ointment	Other anti-fungal creams available	
Herpes zoster	Aciclovir	For pain: Frangipani milk applied from the broken branch of the tree	Apply three times a day but change solution daily

rapidly developing signs of a mass lesion due to toxoplasmosis or tuberculosis, or other symptoms of opportunistic infections. Kaposi sarcoma IRIS has also now been described, and nearly insignificant skin and mucosal lesions can rapidly fungate or cause disfigurement. IRIS can be life-threatening and requires management in conjunction with the ART provider. Patients require treatment of the opportunistic infection and often steroids to transiently dampen down the severity of the immune response. IRIS is an important consideration in a patient who deteriorates soon after starting HAART.

Palliative care physicians must be aware of this and seek professional assistance from HIV physicians for this life-threatening illness.

Figure 11 explains the natural course of HIV and progression to AIDS without ART. ART prolongs the period between the initial marker infection and stage IV of the disease when opportunistic infections, suffering and dying are common. It can be seen that as the CD count falls, the patient is in more danger of dying from an opportunistic infection.

Cryptococcal meningitis

The most feared of all before ARVs was cryptococcal meningitis. Patients who knew they were HIV posi-

tive were afraid of any headache as they had seen their friends die within 1 week of the initial headache. Now if the person reaches a health center, they may be able to obtain antifungal medication. If not, the disease progresses until death. If possible, treat underlying cause, e.g. with amphotericin/fluconazole. The palliative care team controls pain and symptoms bringing holistic care with counseling and preparing the family for the inevitable if the disease is resistant to treatment or treatments are not available.

The headache is typically due to raised intracranial pressure but is not very responsive to steroids. Removal of cerebral spinal fluid for diagnosis can also be used as a therapeutic act by relieving intracranial pressure while waiting for the antifungals to work. Control pain using the analgesic ladder, but morphine is usually required early on and has to be increased if pain breaks through, and reduced if drowsiness occurs, once infection is controlled with antifungals.

Counseling is very necessary for the HIV patient from diagnosis onwards and there are many psychological/social problems that surface in the AIDS journey. The palliative care clinician and team must be aware of the problems of disclosure within the family and out, stigma, marital problems arising from blame and shame, HIV transmission

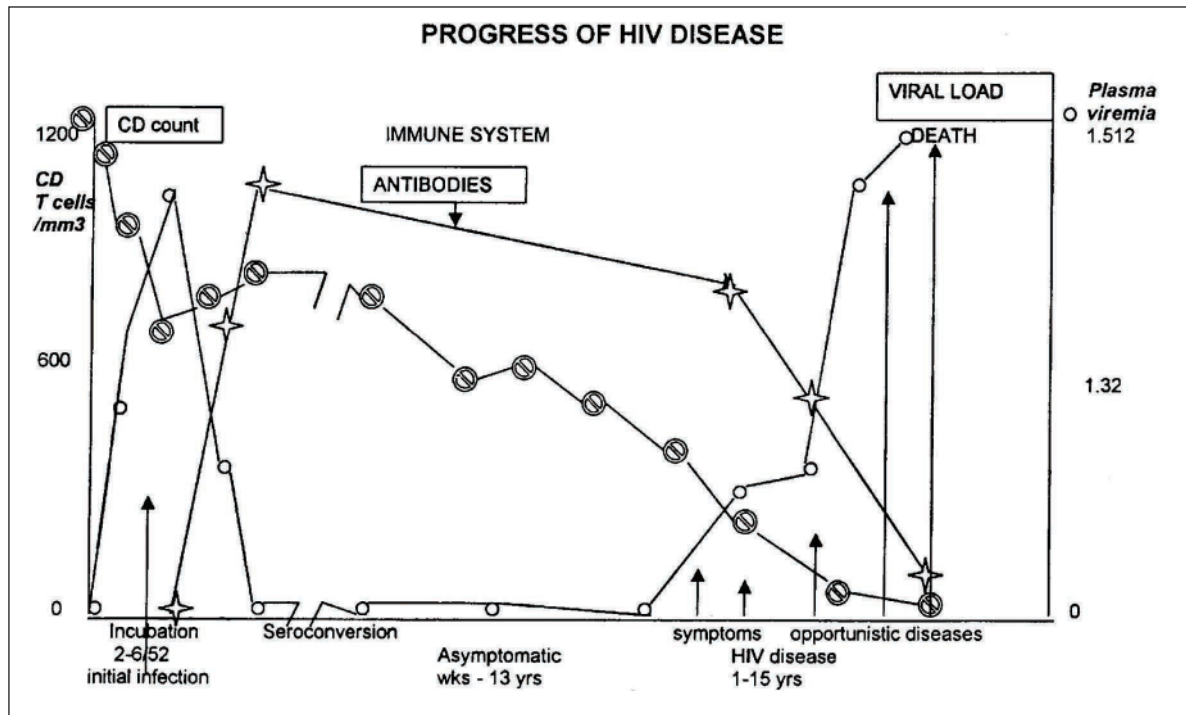


Figure 11 Diagram illustrating the progression of HIV if not treated. Courtesy Prof. Elly Katabira

and protection of the unborn and protection of children born with HIV.

CROSS-CUTTING ISSUES IN CANCER AND HIV IN WOMEN IN LESS-RESOURCED SETTINGS

Psychological/cultural pain

Unraveling contributing factors to unremitting physical pain is essential. However, it is often impossible to understand all the underlying customs and agendas that cause so much suffering. Local health workers often understand but may be diverted by their allegiance to western medicine. It is important for us all to remember our communities and their needs. The advice of a local understanding person for the expat is essential in such matters.

Meaning of the disease

This depends on the cultural approach to such a disease. In the African culture, any disease is considered to be the result of offending someone alive or deceased. This indicates that some recompense needs to be made. This is carried out traditionally in the home village so patients may disappear for some time to do this.

Thus, guilt is attached to any serious illness. Also the role of women in society is often associated with her childbearing ability. Now, the very heart of this function is attacked. The diagnosis of HIV in a patient already struggling with cancer, must be intimated in a most sensitive way, realizing that this is an added burden to the patient and family. Breaking bad news is an essential skill.

HIV and women's cancers can give grief to the patient as well as to the partner. Try and see the couple together. Counseling, together referring to the disease, its prognosis and possible complications, need to be addressed with both partners. It can be difficult to get a husband or partner to come and discuss the problem. Some will refuse to come or accept there is a problem and insist on sexual intercourse even when there is severe dyspareunia or bleeding. Rape within marriage is often accepted and the woman has little say in when or where sexual activity takes place.

Social issues

These cut across all gynecological cancers in resource-poor settings. The woman is often the workhorse of the family. She is often expected to do the cooking, cleaning, caring for the children

and earning money to send them to school and support her husband. If a bride price has been paid then when she is very ill or dying, money maybe refused to assist her as he might be saving up for the next wife.

Finances are low, children cannot go to school and often others in the household are hungry. It is necessary in palliative care to have a 'comfort' fund for such patients. Other supports need to be brought on board as the realities of the local situations are recognized.

For example, in southwest Uganda it was realized that women with cancer of the cervix were dying without any treatment as they were too far away from the only radiotherapy facility in the country. They could not even afford the fare to reach the hospital with radiotherapy. A new scheme was commenced by donors from Canada called the 'Road to Care'. Funding for their transport and support for the patient and a carer while attending radiotherapy, was raised and many patients have benefitted from this with lives extended for some time. Slowly this is being granted to the rest of the country but a scheme like this needs to be taken up by the Government for sustainability.

The greatest fear felt, in spite of pain and symptoms, of a mother is about what might happen to her children after her death. There is fear of lack of school fees so children do not attend. There is fear that the husband marries another wife who will be cruel to these children because they are not her children. There is fear that the husband's family will come and take away all she has saved for the children including their house. These are very realistic fears and the palliative care team can assist by bringing in a lawyer (free if possible) and helping her to make a legal will (with or without a lawyer). Local knowledge for this is necessary.

Spiritual care

Few of us are trained in spiritual issues. However, when dying, the patient may like to confide in one person more than many. Although spiritual leaders and advisors are available, if you have become a confidant to your patient, they will share with you some of their innermost anxieties. Often after listening to these and possibly feeling inadequate, it is good to close the situation by asking how they feel about their relationship to God or their own spirituality. This requires sensitivity to the patient's beliefs.

A prayer may be led by the patient, a relative or you if they request it. However, we must remember to be sensitive to the religious beliefs of each patient. Do not bring Christ into prayers with a Muslim, Hindu or other non-Christian religion. Address the God of us all or the unseen being who guides our life. However, be sensitive to the patient's wants and never suggest praying when the patient or family are at the stage of grief described as 'anger'. Just let them know you will always be there for them.

BASIC PRINCIPALS OF SETTING UP COMMUNITY OR HOSPITAL PALLIATIVE CARE SERVICES

Planning a service for patients with cancer in hospital or communities of resource-limited countries

Before commencing a service in the area of the hospital or the community there are certain facts needed; these facts are found in Table 3. However, because birth and death records are not readily available in most countries, particularly in Africa, we may need to work with 'guesstimates'.

A needs assessment can easily be undertaken by medical students or others of the local community. This is a great help to see the way forward. Who reaches the health service, who does not, and why not? Do women have more confidence in the traditional healer, perhaps the witch doctor, than the western type medical worker? In which case, it is important to get the traditional healer on board with the benefits of early referral to curative or support services. This can be done by inviting them to teach about their role in the health service or by going to them and learning about their approach and their remedies. Some may be reluctant to tell. We need to gain their confidence. Bear in mind that quite a lot of modern medicines come from a traditional setting, e.g. artesunate. Another example is the moringa tree, which is successfully used throughout West and East Africa in malnutrition and home-based care programs. The patient can tell you which herbal laxative has suited them in the past for use to avoid constipation with opioids. You might actually find another useful one with a traditional healer in your area.

Hospital services

Healthcare providers in gynecology are usually working in the hospital and may not be aware that

Table 3 Unknown facts required

What is the population in the country and the catchment area? What percentage are women in the age groups 12 to 100 years?

What is life expectancy at birth?

What percentage are over 65 years and what percentage under 15?

What percentage of commonest cancers can we expect in this population of women?

Where do they live? Where do they prefer to die?

What is the culture?

What social class will we find our women are in? What percentage are living on less than 2\$ per day?

Is the catchment area mainly rural or urban?

What percentage of the population reach a health worker?

What is the maternal death rate? (This gives an indication of use and available health services in the area)

they are only seeing the tip of the iceberg for female cancers. As stated above, the commonest gynecological cancers seen include cervical, breast and ovary. Although cervical and breast cancer are curable in developed countries, it is not the case in under-resourced countries. While in developed countries women are well sensitized about these gynecological cancers and have access to screening and treatment facilities, such awareness is rare in less-resourced countries. Many women seek medical assistance late when the disease is advanced because they are not aware of services available and what health facilities can offer. Manpower in health units, including simple procedures like sensitization and screening is limited. In the rural communities there is a lack of trust in western medicine, having seen their relatives with similar conditions, after admission to hospital, come home in a box. Thus they are discouraged to seek healthcare services. Instead, they often seek traditional healers, because these are easily available (1 to 450 population compared to doctors 1 : 19,000 in Uganda), their services are cheap, modes of payment range from monetary to commodities and they are known to offer quality time, and a holistic approach including cultural beliefs about the illness. Therefore our

women who seek western services, do so late, so palliative care is the only option for relief.

Also, 30% of countries in Africa do not have a radiotherapy machine and oncology is scarce. Thus it is approximated that only 5% can reach such a service and <5% reach it in time for any chance of cure.

The general principles of palliative care

- Caring for a person as a whole.
- Addressing physical, psychological, cultural and spiritual pain.
 - Physical pain may be due to disease or non-disease-related symptoms.
 - Psychosocial pain could be due to loss of social position, job, disfigurement loss of role in the family, traditional beliefs that the disease is because of unhappy gods etc.
 - Cultural pain, patient being sent back to her parent’s home for care, or taking her to traditional healers without her consent, traditional approach of husbands to wives etc.
 - Spiritual pain, patient not being at ease with her God, or people of different beliefs giving conflicting information, i.e. asking her to change religion in search of better favors from God regarding healing etc.

It is therefore important that palliative care providers try to handle the patient with total pain in mind (see Figure 1 on total pain). Healthcare providers should aim to provide and restore the patient’s dignity rather than providing a cure which is often not possible, since patients report in advanced stages of disease. Palliative care supports the patient and family to live as actively as possible throughout the disease trajectory.

Basic principles of setting up community-based palliative care service

Undertake a systematic process for determining the type of palliative care service that will give the best results for this community. Thus an initial needs assessment is important (Figure 12). This helps to address gaps or needs in the present situation and a desired situation that is affordable and culturally appropriate. At the community level begin by:

1. Training/sensitizing the community on predisposing factors, common signs and symptoms and likely services in the community and where they can be accessed. Carry out advocacy

- meetings with community leaders to get their buy in of the project.
2. Involve community leaders, church leaders and let them participate in identifying the needs.
 3. Involve them in the process of setting up a service of community volunteers who are trusted by women to assist them when ill.
 4. Try to link to other community services like home-care projects in HIV, reproductive health etc.
 5. Involve traditional healers from the beginning of the project.

In developing countries, many people are ignorant of the cancer predisposing factors and the signs and symptoms, especially in rural areas. There is need for increasing awareness through trained local volunteers from their own community who can tell the early signs of cancers in their own language. Symptoms that arise are sometimes mistaken as witchcraft bestowed by a person they have offended, alive or dead. This is another reason that the traditional healer is consulted as he understands the cultural context of their fears. It is therefore important that traditional healers are invited to train and be trained on how to refer because they are usually consulted first.

Services in the community

Respected groups in the community include: traditional healers, clan elders, local counsel and church leaders. This is where people with problems go for guidance and advice. It is therefore important to target these groups, sensitize them about (gynecologi-

cal) cancers, give them basic information on signs and symptoms, counseling skills, services available in the area where they can send patients for help. Having obtained the trust of the leaders, it is good to take them through the referral network. Develop and design a simple referral form together, so that it is easy for them to follow. Encourage collaboration and networking between the community and healthcare facilities that are within their communities. Provide contacts of persons in health facilities where services are available. It is particularly important that they have the contact details of a palliative care provider nearest to them for easy accessibility.

Developing community health volunteers for women's cancers

With the blessing of the village or community leader, the community puts forward two or more members who they would accept to assist them if they were sick. These are offered training in basic nursing skills and an understanding of home-based medication for pain and symptom control. These dedicated carers are our eyes and ears in the community. They will offer help not only in basic nursing, but identify those in the village who have never seen a health worker and lie in pain from cancer or AIDS. Then the palliative care team can go down and assess them and make a plan of treatment and follow-up together with the community volunteer worker (CVW). The CVWs also hold presentations at the clinics about the prevention and early detection of cancer for women in the villages.

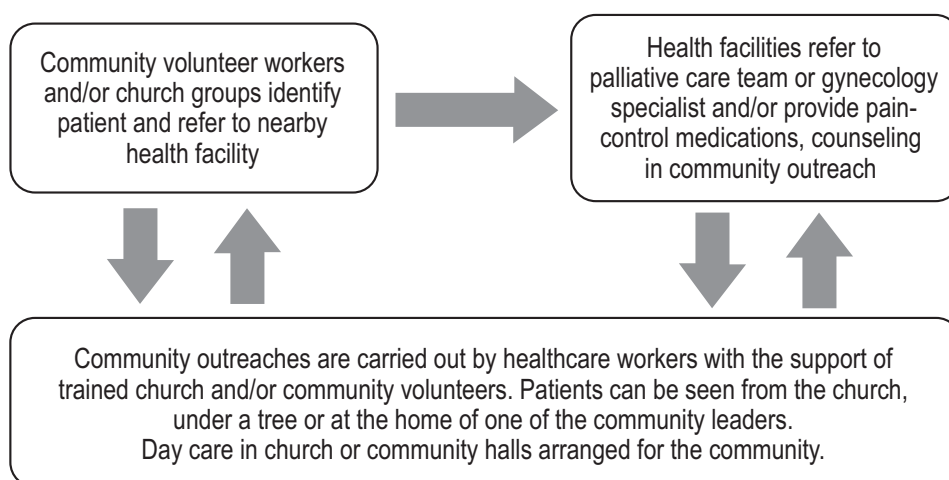


Figure 12 Community model of care

These CVWs receive assistance with their expenses in transport and meet with a palliative care nurse monthly to discuss difficult cases and any problems arising. If there is funding available and it is culturally acceptable for women to ride bikes, then a bicycle is given after a 3-month period of dedicated work. Also a small monthly stipend is given for maintenance of the bicycle. There are benefits here for the patients but also for the CVWs themselves and this has been researched in Uganda^{6,7}.

Collaboration and networking between the community and healthcare providers

Healthcare workers can take services nearer to the community. For example, they can work with the community leaders/religious leaders to provide screening services (if available) in the community. The religious or community leaders can be encouraged to provide space for health workers, together with CVWs, to work from. Religious institutions or groups themselves can support the service from their women's groups such as the Mother's Union etc., offering a meal and transport to the institution's premises, for day care. They can mobilize women to attend for health talks. Then, healthcare workers can organize health talks and training sessions; screening services like visual inspection with acetic acid (VIA) (see Chapter 26) can also be arranged and where possible, patients can be referred back to their village CVW for continued support or to palliative care team for further management of symptoms.

Hospital palliative care services

The gynecology team will need the support of a palliative care team. However, if not available it is recommended that palliative medicine is part of the training for all healthcare providers. Thus, they can actually commence palliative care before the patient leaves the hospital and relate to any community services available to support her on discharge.

When available, the hospital palliative care teams play vital roles in identifying patients that need palliative care services and also in coordinating appropriate care. They work with the different specialties/departments and networking organizations, to ensure the patient and family receive the required affordable and appropriate services to improve their quality of life. This is coordinated at a meeting to

discuss patients about to be discharged, with the hospice/home palliative care team.

As most women wish to be at home with their families, assessment of the home should be carried out before discharge and the family encouraged to be involved with care and decisions regarding care. The palliative care team with the CVWs can now take over care in the community.

Training the community palliative care team

Hospital palliative care teams in resource-limited settings may consist of fewer professionals, than in the western world. The team consisting of nurse, doctor, spiritual care giver, counselor, social worker, occupational therapists and physiotherapists are rare and often the nurse is the main person having to combine many roles. Working with the community, she will train CVWs whom s/he will work with in the villages. S/he will equip them with basic assessment skills so that they will identify patients with palliative care needs, including pain control. S/he will equip them with basic nursing care skills that will help them to continue providing care to patients in the community. The CVW also supports the palliative care patient through their disease trajectory. The CVW will refer and consult with the nearest palliative care team who will come and visit the patient in the home when too ill to attend a center or clinic. The palliative care team, as well as caring, will advocate for a continuous supply of palliative care medications including oral morphine, the drug of choice for severe pain control, recommended by WHO. Patient and family are part of the team and are always the center of all we do.

How to set up a hospital palliative care team

1. Sensitize the hospital administration so that they buy the idea and provide support to the hospital palliative care team.
2. Encourage administration to identify space that is easily accessible where patients will be seen. Palliative care medications should be placed in an easily accessible but secure place as oral morphine has to be in a double-locked cupboard.
3. All trained palliative care staff or those sensitized on palliative care should be brought together to plan palliative care service provision in their hospital, i.e. patient care, CME (continuing medical education), case conference etc.

4. They will need to identify a leader who will coordinate them and plan activities.
5. Palliative care clinic days can be specified, so that healthcare workers know where and when to refer patients, and for patients to know when and where to go for review.
6. Funds need to be found, either through budgeting within the annual health budget or through donor agencies.

Members in the palliative care team encourage staff to refer patients with palliative care needs to them, they also visit different units or departments with an aim of identifying patients with palliative care needs but also establishing rapport with other staff in the units. Their leader acts as a liaison in the hospital and in the community.

Effective collaboration between the community and healthcare system minimizes patients suffering and improves care. Figure 13 gives an example of a hospital-based palliative team.

SUMMARY

Women's cancers are the commonest cancers in low-resource settings today. Thus, it is important to recognize what treatment options are available in surgery and radio-oncology. Many countries have very limited curative services, but the patient's quality of life and relief from suffering is paramount for the medical team.

All services require the blessing of the Ministry of Health if they are to be sustainable. Thus, it is essential the Ministry is aware of the statistics presenting the needs and that palliative care is recognized as an essential clinical service for all in need. This in place, the Ministry of Health can support a continuous supply of medications for palliative care delivery and the training of the health professionals to be prescribers when doctors are scarce, and to be specialists in palliative care.

USEFUL WEBSITES

African Palliative Care Association: www.apca.org.ug
 Hospice Africa Uganda: www.hospiceafrica.or.ug
 Pallium India: www.palliumindia.org
 International Association of Hospice and Palliative Care: www.hospicecare.com

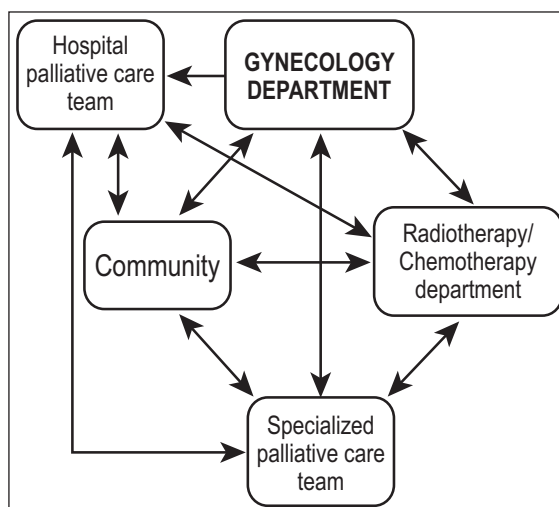


Figure 13 Hospital palliative care model

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