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FIGO CANCER REPORT 2015

## Palliative care in gynecological cancer

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## 1. Introduction

According to the WHO definition, “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 treatment of other problems, physical, psychosocial and spiritual” [1]. In addition, “Palliative care is required from early in the disease course, can be delivered alongside potentially curative treatment, and continues to include end-of-life or terminal care” [2].

The WHO definition highlights fundamental principles. It “affirms life and regards dying as a normal process”; and “intends neither to hasten nor postpone death” [1]. It also emphasizes “impeccable assessment” as essential for effective management.

Palliative care cannot be left solely to primary or palliative care physicians or to nurses. It needs to be actively embraced by all providers including oncologists and other specialists and integrated into all areas of medical care [3,4]. Oncology follow-up visits are the ideal place to introduce the concept and every decision about treatment should take palliative or quality of life considerations into account. Giving up curative treatment does not mean giving up hope or concern, nor does an attempt at curative treatment mean that palliative care should not be offered. Discussions about end-of-life care, refusal of care, and advance planning have cultural dimensions that require great sensitivity and thought, but opening these discussions is critical to the best end-of-life care [5].

Palliative care is an approach that embodies compassion [6]. It is not dependent on sophisticated equipment, expensive buildings, or technology, and can be applied in any setting. It can easily be offered in resource-poor settings as well as in countries with highly developed healthcare services.

In practice this depends on a significant shift in focus. Many societies avoid and fear aging, death, and dying. Huge advances in medicine have fed the belief that medicine can rescue everyone. Medicine has a responsibility to explore and address these fears as well as embrace and advocate for the best of palliative care.

Some 80% of countries globally have low or very restricted access to strong pain medications [7]. Although morphine is the gold standard and the cheapest drug available, it is still illegal or unavailable in many countries [7]. The African Palliative Care Association and others are working actively to change this [8].

In addition to end-of-life issues, gynecological cancer presents many long-term problems related to disease and treatment [9]. Both aspects require a palliative focus.

## 2. Therapeutic relationship: The cornerstone of care

People have a deep need to be seen and heard. This in itself is therapeutic. Very often it is not *what* was said but *how* it was said that is remembered. Good communication depends on sensitivity, authenticity, and genuine human relationship [10]. Healthcare providers need to convey that they care and that they will be there for their patients whatever path they take. Patients can fear being abandoned if cure is no longer a possibility, and providing the security of a continuing relationship with their trusted caregiver is a key component.

Dealing with death and dying requires us to constantly confront our own fears. Physicians can struggle to overcome not only their teaching, which emphasizes rescuing and curing, but also their own fear of disability and dying. Caring for the dying invites us to look at our own lives, values, attitudes, and beliefs to care compassionately for the scope of needs our patients encounter on their cancer journey.

## 3. Ethical Issues

Ethical issues relate to both patients and context of care. Our primary ethical responsibilities are to benefit (beneficence) and not harm (non-maleficence) while making sure patients understand and can choose among options for their care (autonomy). In palliative care the treatment goals are primarily ameliorating symptoms, alleviating pain and suffering, and helping patients understand the disease course. These become our ethical measures for success. Care of symptoms and attention to quality of life are goals regardless of the curability of the cancer [11], and have been shown to improve quality of life and mood, and even lengthened survival in some studies [11].

Preserving patient autonomy—the ability to make authentic decisions regarding their own health care—is essential, though often difficult. Societal, religious, and familial pressures on patients and caregivers have the potential to overwhelm decision making. The classic example of family demanding “everything” be done to save their mother, while the mother wants to have no resuscitative measures with her terminal disease illustrates how this tension can present. Women are at the center of families and often make choices that benefit the family before themselves—denying themselves adequate pain or other care because of cost or inconvenience to the family. Our role is to advocate for the patient's best interests, including encouragement to ask for what she wants and needs.

Globally, lack of access to adequate pain control, palliative care options such as radiation, or advanced pain control techniques create

ethical challenges related to context of care. Regulations that limit access to narcotic pain management at the end of life are harmful to patients. Providers must advocate actively for policies and just allocation of essential medication and palliative care support in every resource setting [12].

#### 4. Interdisciplinary team work

Palliative care emphasizes whole person medicine and it is impossible for one person to do this alone. Effective palliative care depends on good teamwork. As an ideal, the basic care team should consist of a doctor, professional nurse, and social worker. The team can benefit from a dietician, occupational therapist, physiotherapist, massage therapist, and creative artists, as well as a “gynecologic oncologist, a radiation oncologist, a radiologist, an interventional radiologist, a pain specialist from hospice services, and/or a palliative care physician” [13]. In many settings this is not possible—but engaging cross-disciplinary health providers provides different perspectives, ideas, and approaches that can benefit patient care. Incorporating spiritual care into the team helps address not only the patient’s but their family’s and even the team’s need to find meaning in the process of care and dying and transcend suffering.

Constant exposure to death and dying can rapidly lead to provider burnout unless the load is shared. Teamwork can be challenging and requires good leadership and constant review. Well implemented it greatly improves quality of care, stress, and work satisfaction. Poor team work can contribute to burnout. Five essentials are: trust, two-way communication, respect, roles, and responsibility. Additional qualities of good team work include positive leadership and management; personal rewards, training, and development; skill mix; supportive team; clarity of vision; and respecting and understanding roles [14].

#### 5. Pain control

“As with most incurable cancers, pain control is the dominant issue and must be addressed. Judicious use of narcotics, radiation, and nonnarcotic pain remedies is essential” [12].

The goal of pain control needs to be discussed. For example: is the goal to preserve normal function and ability to work—and what is required for that? Is it to provide relief from neuropathic pain? Each situation requires a unique approach that will often be multimodal [15].

Understanding pain type, acuity, inciting and diminishing factors is key to pain management. Prior drug interactions and physical, mental, and contextual status should all be reviewed initially and on an ongoing basis (Table 1).

The axiom of pain control is to treat different types of pain differently. Pain from cerebral swelling with brain metastases includes corticosteroids to reduce swelling and enhance function, as well as analgesic medications. Pain from abdominal swelling can benefit from massage for back strain (due to abnormal posture), abdominal massage, or heat as well as analgesia. Neuropathic pain may require early medication, massage, and physical therapy to improve function. Treatment of anxiety may reduce the need for analgesics.

When medication is required, the WHO pain ladder [16,17] remains the standard, with non-narcotic therapies at its base. If the management plan is not meeting pain needs, then reassessment of all elements is required—before adding narcotic medications. Successful pain control depends on around the clock base relief, together with rapid acting breakthrough medication for intermittent increases in pain or desire to increase activity (Table 2). Finally, it is important to anticipate, assess, and manage any adverse effects of medication, in particular, constipation, nausea, and vomiting

In places without access to narcotic medications, pain management (particularly for end-of-life care or acute cancer pain) is exceptionally difficult and a tragedy for the patient and her family. Maximal use of all available medication, liberal use of additional means of comfort

**Table 1**

Key elements to review in planning a pain management strategy.

Elements to consider	
What is the goal of pain management?	Functional level, desired sensory levels, time specific goals such as a specific event. Priority among goals
What is the type of pain?	Neuropathic, tissue damage, pressure, musculoskeletal, inflammatory
Duration, level, and modifying factors	Constant, occasional, related to movement, morning, evening, etc. Use a scale to measure level of pain
Prior management programs that have been effective	Heat, cool, massage, physical therapy, types of pain medicines
Reactions to pain or psychotropic medicines	Allergies, nausea, constipation, depression, other adverse effects
Overall health that may impact choices for pain management	Depression, anxiety, or other psychiatric conditions; addictions; renal and hepatic function; central nervous system function; respiratory distress; physical performance status; nutritional status; skin status
Contextual modifiers	Lack of insurance, finances, or limitations; religious beliefs regarding suffering; lack of care givers; safety of home setting

(massage, heat, physical therapy, positioning), as well as ongoing advocacy for rational narcotic access to prevent suffering, become essential parts of treatment [18].

#### 6. Other symptoms

Each disease has its own unique picture. Symptoms may be disease or treatment related. “Treatment...often has serious lifelong side effects, including cystitis, proctitis, intestinal strictures, fistulas, vaginal agglutination/sexual dysfunction, and chronic pain” [9].

**Table 2**

Elements of a cancer pain strategy.

Strategy	
Treat different types of pain differently. Use multimodal approach and combine as needed.	Neuropathic pain: anticonvulsants, antidepressants, gabapentinoids, transcutaneous stimulation. Acute inflammation: corticosteroids. Anxiety and depression: anxiolytics and antidepressants. Tissue damage pain (nociceptive): scale of anti-inflammatory to narcotic medications. Bone metastases/brain metastases: consider local radiation therapy. If available, for localized pain, blocks and indwelling epidural analgesia.
Give the medication at regular intervals	Provide a base level of pain control and accommodate for breakthrough pain.
Use the least invasive form of administration available	Oral, topical (patches and creams), sublingual forms preferred over subcutaneous or intravenous forms.
Adjust to comfort and individual goals	The patient is the best judge of whether pain control is meeting her goals, and individual tolerance and needs vary widely
Make liberal use of additional supportive care	Consider the role that massage, heat, meditation, physical therapy, positioning, and alternative therapies (aromatherapy, music therapy, etc.) and spiritual care can play to assist pain and anxiety control.
Anticipate adverse effects and plan for them	Constipation, somnolence, nausea can all accompany pain control and planning ahead can improve outcomes.
Anticipate changes in needs	Use a pain scale and follow over time, as needs will change both up and down with treatment or progression of disease

General management principles [19] are:

- Appropriate assessment
- Explanation to patient and family at all stages
- Correct reversible factors
- Consider disease-specific palliative therapy
- Non-pharmacological interventions
- Appropriate first line treatment
- Adjuvant or second line treatment
- Regular review with involvement of the interdisciplinary team...or more experienced clinician; plus
- Essential medication in palliative care (Table 3).

### 6.1. Loss of appetite and fatigue

Eating is a fundamental human experience and feeding people is a natural way of showing care and support. Many family members struggle to accept that the patient no longer wants to eat and this causes significant distress. If aiding the appetite will improve the patient's quality of life or the patient has specific short-term goals, then progestins or steroids to stimulate appetite may be considered.

### 6.2. Edema and ascites

Edema is common in late-stage gynecologic cancers owing to low protein and lymphatic blockage, and is difficult to treat. Regular lymph drainage massage and limb wrapping or support stockings/sleeves may assist comfort.

Ascites may require repeated drainage or an indwelling catheter, although this must be balanced against the additional loss of protein and increase in edema that result. High-dose spironolactone (100–400 mg per day) with furosemide may improve ascites.

### 6.3. Nausea and vomiting

Common causes are mechanical bowel obstruction, infection, metabolic disturbance (including hypercalcemia), renal failure, and occasionally cerebral metastases [9].

Bowel obstruction is a frequent occurrence, especially with ovarian cancer, but few patients are amenable to surgical intervention and must be chosen carefully after balancing patient preference, likelihood of surgical success, prognosis, and risk factors. A simple colostomy with progressive pelvic cervical cancer may give relief quickly without

a long surgical recovery time. Given the multiple sites of obstruction, particularly with progressive ovarian cancer, surgery is rarely used. Nasogastric tubes are discouraged because they are uncomfortable, but nasogastric or percutaneous gastric tubes may be helpful when other approaches are not helping [20]. Antiemetics and medications to reduce intestinal output are available for subcutaneous, rectal, oral/lingual, and intravenous use, and continuous or around-the-clock use is the most effective approach.

Often people cannot tolerate the idea of not being able to eat. Even in the presence of total gastric outlet obstruction, many patients prefer to eat a little and are prepared to tolerate vomiting rather than stop eating completely.

### 6.4. Constipation, diarrhea, fecal incontinence

Constipation, whether disease or medication induced, is a major cause of discomfort and suffering. Pain medication may complicate management, and a laxative regimen should always be provided along with these medications, assuming there is no obstruction. Regular assessment and repeated education sessions are necessary.

Diarrhea may be a short- or long-term consequence of treatment, and treatment should be focused on the etiology. For example, simple lactose intolerance after radiation or long-term narcotic-based regimens to repress bowel motility have different solutions.

Fecal incontinence has a major impact on quality of life, and bowel regimens or rarely surgical diversion can help. For the most part, local attention to hygiene and skincare provides the best palliation for this symptom from surgery, fistulas, or disease.

### 6.5. Incontinence, urinary retention, urinary tract infection

Urinary incontinence may result from spinal cord compression, sacral plexus involvement, bladder infiltration, or fistulas. Skin protection using barrier creams is essential. Urinary catheters, suprapubic catheter, or nephrostomy are considerations. Each of these comes with increasing complexity of management for the patient and caregivers and may be unaffordable.

Urinary tract infection is common, with or without catheterization and should be actively checked and treated.

### 6.6. Vaginal discharge and bleeding

Evaluation of a new discharge is always warranted as it may represent fungal or bladder infection, which can be treated. Discharge from tumor growth, bleeding, or fistula is very upsetting to the patient and her caregivers. Collaboratively developing a plan for hygiene and providing a sense of control, particularly with vaginal bleeding, facilitates management and opens the door to further discuss progression of disease and expectations.

Minor bleeding wounds may respond to topical adrenaline. Cyklokapron (tranexamic acid), radiotherapy, or occasionally interventional radiology-based embolization, if available, may be useful to stop bleeding. Direct pressure may also assist, for example a vaginal pack and use of Monsel solution or other topical agents for cervical cancer bleeding. Symptomatic anemia can be treated with blood transfusion if resources allow and if the benefits in terms of symptom relief and quality of life are of reasonable and ethical duration.

Hemorrhage as the final event is one that can traumatize all who witness it. In patients where this is a possibility, family members and healthcare providers should be prepared.

### 6.7. Shortness of breath

Air hunger and shortness of breath may result from anemia, infection, pleural effusion, lung metastases, or heart failure. Diuretics are

**Table 3**  
Essential medication for palliative care.<sup>a</sup>

Requirement	Use	Medication
Pain	General	Paracetamol, tramadol, codeine, morphine (a WHO essential medicine), fentanyl.
	Bone pain	Ibuprofen, indomethacin.
Neuro-psychiatric	Neuropathic pain	Gabapentin (neuropathic pain).
	Anxiety	Lorazepam, diazepam.
	Insomnia/restlessness	Zolpidem, midazolam, haloperidol.
Gastrointestinal	Depression	Amitriptyline, citalopram.
	Constipation	Laxatives (senna, liquid paraffin, glycerin and dulcolax suppositories, fleet enema).
	Diarrhea	Immodium, codeine.
	Nausea/vomiting	Metoclopramide, hyoscine butylbromide, haloperidol, 5-HT3 antagonists, steroids, proton pump inhibitors
Other	Inflammation	Dexamethasone, prednisolone.
	Fluid/ascites	Spironolactone, furosemide.
	Bleeding	Adrenalin, cyklokapron.

<sup>a</sup> For more details see the IAHPC List of Essential Medicines for Palliative Care [22].



seldom helpful except in heart failure. Fanning, morphine, and oxygen bring symptomatic relief, as does anxiety control.

Pleural drainage and pleurodesis may be helpful for comfort and to prevent recurrence of a pleural effusion if the condition of the patient warrants this.

#### 6.8. Deep vein thrombosis

Prevention is preferred with passive or active movement. Sequential compression devices and anticoagulant therapy need to be considered in the context of the patient's prognosis, quality of life, and living conditions, and balanced against the risk of bleeding.

#### 6.9. Psycho-spiritual

Anxiety, depression, fear, denial, loss of body image, sexual frustration, and insomnia are almost always present to some degree and can significantly impact on physical symptoms. Treatment approaches are both pharmacological and non-pharmacological.

Gynecological cancer strikes deep to the core of what it means to be a woman. It is hidden, private, deep-seated, and may be associated with deep shame. Additionally, women try to avoid causing distress to their families and one of the greatest challenges to their identity can come from being the one needing care rather than being the care giver. Great sensitivity is needed in handling these women.

Existential fear in the face of death cannot be avoided and is part of the human condition, but the more open the discussion and the more active the personal support, the more ease the patient may feel in the transition. Denial may need to be more actively confronted when it interferes with proactive planning for future care of the patient or minors.

Spiritual support, essential and integral to holistic care, must be individualized according to the patient's religion, culture, and belief system. It cannot be imposed or directed by the caregiver's views.

### 7. Social considerations

Detailed social assessment of needs, preferably with a social worker is imperative. Particular attention should be given to financial needs, needs of children, care, legal issues and wills, unresolved family conflict, and future planning. Social problems are often the main cause of anxiety. Sometimes simple assistance, like a letter to an employer, is all that is needed.

### 8. Palliative care emergencies

Detailed discussion is beyond the scope of this article and can be found in the references [21]. Extremely rapid treatment is needed in the case of hemorrhage, hypercalcemia, superior vena cava syndrome, and spinal cord compression, but we must still weigh the potential benefits and harms particularly with patients for whom survival is already expected to be short.

### 9. Pressure and wound care

Good care can prevent skin pressure ulcers. The sacrum and heels are vulnerable areas in bed-bound patients and need frequent evaluation. Simple movement on a regular basis will assure pressure relief and enable local circulation. Sheepskin or other "boots" and pads also improve circulation.

Wound healing can be assisted by multiple means. Keeping wounds clean and dry is the basis of care. Continuous vacuum dressings have significantly improved time to wound closure for open wounds and may also be helpful in managing discharge from malignant skin lesions (cutaneous metastases) where no further therapy is planned.

### 10. End-of-life care

Cultural, religious, and spiritual views determine how patient and family view the information that death is approaching. Good timing and sensitivity are imperative. Each family unit is unique and there are no blanket rules but clear, honest, compassionate communication is needed. People vary in how much they need and want to know. Usually the patient knows what is happening and may or may not want more information. Generally family members welcome honest communication and frequent updates are vital. Even in the late stages, include the patient in the discussion and do not assume that lowered level of consciousness means lack of awareness or feeling.

Comfort is the major factor determining treatment decisions. Physical and psycho-spiritual needs must be assessed regularly and unnecessary medication and intervention discontinued. Common end-of-life symptoms are pain, nausea, vomiting, agitation, and respiratory difficulty. When oral medication is no longer possible, sublingual, rectal, and subcutaneous administration are options. A restless patient may have urinary retention, which can be relieved. Impeccable and gentle nursing care is imperative with special attention to turning, wet linen, diapers, bowel, skin, and mouth care.

Grief is expressed in myriad ways, some of which can be disturbing to the patient or others around her. Challenges can arise when religious or cultural taboos forbid the discussion of death as a possibility, let alone a probability. Some groups see it as a sin to give up hope or even to think "negatively." These beliefs can present major challenges to appropriate planning and management. Wherever possible provide information about the dying process, what to do in the event of death and the availability of bereavement support.

### 11. Conclusion

If the principles of palliative care are understood they can be integrated into all levels of health care and all levels of healthcare training. The principles are not complicated and once the concept is embraced, shifting focus from curative to palliative should ideally become as simple as watching the sun rise and the sun set. Palliative care requires both the art and science of medicine and is a pressing universal need.

### Conflict of interest

The authors have no conflicts of interest.

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