



National Hospice and Palliative Care Organization
Palliative Care Resource Series

**PALLIATIVE CARE FOR CANCER
PATIENTS: PRACTICAL TIPS FOR
HOME BASED PROGRAMS**

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Palliative Care for Cancer Patients: The Need

Cancer is the second leading cause of death in the US, following heart disease. More than 500,000 Americans are expected to die from cancer and 1.5 million Americans are expected to be diagnosed with cancer in 2016. Lung cancer is the leading cause of cancer death in both males and females followed by prostate cancer in males and breast cancer in females. Overall, the five-year survival rate is on the rise. Palliative care is an integral part of care for these patients, including survivors, and can improve their quality of life and provide support for their families (1).

This paper will provide background information including the stages and causes of cancer; identify common palliative care needs; describe tools for assessment; and discuss palliative care for patients at home.

Definition of Cancer and Staging

A group of diseases that share the common feature of uncontrolled proliferation and spread of abnormal cells are referred to as cancers.

Staging of cancer relates to the extent of the disease within the body. Cancers are commonly staged from stage 0 to IV. Stage 0 cancers are confined to the primary site and have not spread to neighboring tissues whereas stage IV cancers represent the most advanced, with distant spread (1). Depending on the type of cancer, some advanced cancers might be curable while some early cancers may not.

Relevant Pathophysiology

Genetic predisposition, environmental exposure and lifestyle can potentially predispose a person to cancer. While some cancers run in families, most do not. Environmental factors such as smoking can lead to cancer. There is also growing evidence of the association between diet, physical activity and cancer (1).

Clinical Course

The clinical course of cancer is determined by the type of cancer, its stage, the treatment options and the choices made around them. Patients have varying responses to treatment/s. Complications from the disease can also vary from patient to patient and impact the overall outcome and clinical trajectory.

In general, patients with progressive cancer tend to show a steady decline in their condition with a steep decline as prognosis worsens. The change can seem very dramatic for patients and families. Often patients will report adequate/fair functional status, with a notable loss of various abilities over a relatively short span of time.

Most patients with a cancer diagnosis die from complications of the disease rather than from the cancer itself. Patients and their families need continual education on the disease process since 'the focus can often be around the tumor (e.g. size). In addition, the overall functional status of a patient can greatly influence eligibility to receive chemotherapy. Chemotherapy itself can lead to complications and a decline in functional status. Therefore, risks and benefits should be continually explored and communication about current status is the key in managing cancer patients.

Common Palliative Care Needs

Although effective anti-tumor therapy can reduce tumor size, pain, and prolong survival, the symptom burden in patients with cancer may be caused by a combination of the disease and its treatment.

Cancer treatment may include surgery, chemotherapy, and radiation.

- Interventions to counter the side effects of the cancer treatment may include transfusions, antibiotics, growth factors, anti-emetics, and opioids for relief of mucositis pain.
- Newer anti-tumor drugs have fewer cytotoxic side-effects, are often administered orally, but are associated with side-effects that include severe fatigue, hormone dysfunction and skin disorders.
- Radiation therapy directed at bone metastases can effectively improve pain control with a single treatment.

Non-pharmacological interventions directed at maintaining function, independence, and psychological well-being are important, whether patients are receiving disease –specific treatment or not.

- Depending on the individual's prognosis and function, patients with cancer may benefit from occupational or physical therapy and exercise.
- Frequent snacks with calorie-dense foods and nutritional counseling are helpful for maintaining weight and decreasing chemotherapy related side-effects, particularly in patients with lung or gastrointestinal cancers that are at risk for cachexia.
- Expressive supportive counseling may be complemented by the special skillset of chaplains, social workers and psychologists to address spiritual and psychological distress.

TOOLS FOR ASSESSMENT OF SYMPTOMS/FUNCTIONALITY/PROGNOSIS

Assessment of Symptoms

Symptom assessment is important at every visit because patients will often volunteer few symptoms relative to their total symptom experience. In North America, the 10-item Edmonton Symptom Assessment Scale (ESAS) is used most frequently in palliative care clinical practice and research (2).

- The ESAS can be administered in less than 5 minutes and will identify symptoms that may otherwise be missed.
- Symptom scores ≥ 7 are generally considered severe and those ≥ 3 are moderate. Moderate to severe symptom scores require an additional focused assessment.
- The ESAS has been shown to be useful in identifying symptoms in patients with advanced cancer typically seen in palliative care or hospice, and in patients still receiving anti-tumor treatment. In large populations, the ESAS detected a high prevalence of multiple symptoms in ambulatory cancer patients, similar to those reported in typical palliative care populations (3).

Assessment of Opioid Risk

There are increasing concerns about substance abuse and diversion in patients with cancer, even at the end of life (4). There are no guidelines regarding the use of opioid risk questionnaires or other screening tools in patients with cancer. There are several tools available including the CAGE-AID, the screener and opioid assessment for patients with pain-short form (SOAP –SF) and Opioid Risk Tool (ORT) that take less than 5 minutes to administer (5).

- These tools need only to be administered once.
- Using these questionnaires, about 1 in 5 patients with cancer may be identified as ‘at risk’ (6).
- Screening ‘positive’ has been associated with aberrant behavior, prolonged opioid use, higher morphine equivalent daily dose, greater health care utilization and symptom burden.

Assessment of Prognosis

An accurate prognosis is important to clinicians, patients and their families. Planning, goals of care discussions and resource allocation may be influenced by a patient’s prognosis. The Palliative Performance Scale performs well as a predictor of prognosis and has been used in hospital acute care settings and in hospice. Several other prognostic tools have also been shown to be helpful for decision making. A prospective study of 549 patients compared four prognostic tools including the PPS and suggested they all accurately identify survival (7).

Using a prognostic assessment is helpful since physicians are generally overly-optimistic about survival of their patients (8), and a study of over 21,000 hospice patients suggested the PPS was a better predictor of short-term survival than experienced nurses (9). The PPS has been used in patient populations that include cancer and non-cancer conditions (10).

PALLIATIVE CARE FOR CANCER PATIENTS AT HOME

Although the disease trajectory is similar for most cancers, the progression of disease is dependent on multiple factors including the number of comorbidities and the patient’s overall functional status. A patient’s function usually declines gradually until the last months of life at which time it deteriorates at a much quicker rate. Typically high symptom burden is most evident during the last 6 months of life (11).

Diagnosis and Treatment at Home

Each specific cancer and the corresponding treatment generate a variety of symptoms which need to be closely managed in order to maintain quality of life during and after treatment. Some symptoms are relatively easy to control with medications such as metoclopramide, for non-chemotherapy related nausea, while others such as depression and pain require a multimodal approach combining pharmacological and non-pharmacological interventions. A few select symptoms such as fatigue and poor appetite are likely to worsen, in part, because there are few therapeutic options. The involvement of palliative medicine has been shown to prolong life in patients with non-small cell lung cancer (12), and the ASCO has recommended that palliative medicine should be integrated into the care of patients with advanced or metastatic cancer (13).

Likewise, hospice care should be an integral option in the cancer care continuum. It is important not only for the patient but also the family members who may be able to receive bereavement services after the patient's death. Some hospices do not require a patient to be a DNR and will offer chemotherapy, antibiotics, TPN and tube feeds to patients on hospice. The available hospice services in each community need to be well understood so that the patients can best benefit from the services.

Patients often choose to be in the comfort of their own homes throughout the treatment process. In order to be successful in managing acute symptoms in the home, effort needs to be placed on preventing crises. By providing appropriate medications and educating patients and family to effectively identify and self-manage symptoms, acute crises can be averted. In addition, this focus will result in improving the patient's quality of life while avoiding inappropriate admissions to the hospital and visits to the emergency room.

The Team

The delivery of palliative care in the home requires careful planning and care coordination between all involved medical specialties as well as with family, caregivers and psychosocial supports. The team involved with providing care may include Palliative Care, Primary Care, Oncology, and any specialty providers involved in treating the patient's comorbidities. In addition, community partners such as Home Care, Parish Nurses and the Area Agency on Aging should be utilized.

Advance Care Planning

Advance care planning, including the expected disease trajectory, should be discussed with the patient throughout the disease process as the patient's overall condition will continually change. Family or surrogate decision makers should be involved in these conversations so they are prepared to make appropriate decisions if the patient becomes incompetent during a crisis. Quality of life as defined by the patient should be central to all decisions. Discussions about the extent to which a patient is willing to compromise his/her quality of life by undergoing aggressive treatment will help guide care.

These discussions are often more effective in the patient's home as home often provides a more emotionally safe environment. The patient is able to feel more in control of the conversation in his/her own home and subsequently is encouraged to be more open and honest about his/her values and emotions. House calls also provide insight into the patient's true functional ability, allowing the practitioner to better guide the overall care plan.

CLINICAL

Pertinent areas of special focus on initial and subsequent visits at home (may depend on the frequency of visits):

Suggest the initial visit involve all palliative care team members.

1. Physical

■ Vital signs

Include the 5th vital sign as part of the ESAS: pain

Increased pain may be related to tumor e.g. new bone metastases or patient related e.g. delirium, 'chemical coping', and existential suffering. They each require an individualized multimodal treatment approach

■ Share all clinical findings with oncology to coordinate subsequent treatment. Remain knowledgeable of the side effects of specific treatments. Be aware of any new symptoms that may signify metastases or disease progression.

■ Assess each of the patient's co-morbidities and their effect both on the patient's ability to tolerate treatment and on the patient's quality of life.

■ Screen for oncologic emergencies such as hypercalcemia, brachial plexus neuropathy, syndrome of inappropriate antidiuretic hormone, spinal cord compression, superior vena cava syndrome, febrile neutropenia, disseminated intravascular coagulopathy, tumor lysis syndrome, pericardial effusion.

■ Delirium

Avoid sedating medications such as benzodiazepines, use haloperidol for symptoms of delirium, consider opioid rotation to a lower equianalgesic dose.

■ Increased Weight and fatigue

Consider dexamethasone with a prognosis of less than 8 weeks and increased symptom scores.

■ Functional status: use one tool consistently. Suggest use of Palliative Performance Scale (PPS) Monitor for change- important for prognosis.

■ Screening for symptoms: use one tool consistently. Suggest use of Edmonton Symptom Assessment Scale (ESAS)

Symptoms are often missed if a screening tool is not used. Should be used at every visit.

■ Medication reconciliation –review how each medication is dispensed.

Assess ability to manage medications. Confirm the understanding and purpose of each medication and ensure adequate supply to optimize compliance. Review the potential side-effects and risk- benefit ratio.

■ Intravenous infusions or hypodermoclysis

Enable patients to stay at home. Used when patients are unable to take medication orally (e.g. Malignant bowel obstruction, requiring opioids, haloperidol and other medications for symptom management).

■ Review records including ESAS and PPS to obtain a clinical baseline

Essential to know baseline to be able to identify significant changes.

Any changes in the above will require a more thorough assessment to avoid further decompensation or to escalate care, such as setting up an appointment with Oncology, especially if the patient has continued receiving chemotherapy.

2. Additional needs assessment

■ Emotional/financial support screening

Request social worker follow up, if needed, in addition to routine social worker visits.

■ Spiritual needs screening

Request chaplain visit, if needed, in addition to routine chaplain visits.

■ Caregiver screening

Ensure social worker and chaplain support to caregiver(s). Monitor for caregiver burn out.

- ◆ Optimize all support to the patient and the caregiver from the time of initiation of the program.
- ◆ All community resources need to be identified so the team is able to connect them with the patient and caregivers.

■ Symptoms

Evaluate individual symptoms with a standardized scale such as the Edmonton Symptom Assessment Scale (ESAS).

- ◆ **Pain:** Distinguish between types of pain (visceral, somatic, bone, neuropathic). Consider non-pharmacological approaches.
- ◆ **Fatigue:** Rule out reversible causes such as anemia, metabolic imbalance, medications, infection, insomnia, depression. Consider impact of comorbidities.
- ◆ **Gastrointestinal:** Monitor dysphagia and weight loss. Treat nausea/vomiting around the clock to improve nutritional intake. Address diarrhea to avoid dehydration. Proactively prevent constipation if opioids are involved.
- ◆ **Dyspnea:** Rule out reversible causes including anemia and pleural effusions. Appropriately address anxiety and deconditioning.

■ Functional status

Assessing Functional status: Use one tool consistently such as the Palliative Performance Scale (PPS). Include evaluation of the individual elements of the patient's functional status:

- ◆ **Poor appetite/Loss of weight:** Assess for and treat primary cause including nausea, constipation, diarrhea, dysgeusia, dysphagia, fatigue, depression. Discuss diet and nutritional supplements. Involve nutritionist as part of your team.
- ◆ **Dehydration:** Evaluate for IV fluids.
- ◆ **Sleep disorder:** Determine pattern of and underlying cause such as anxiety, depression, pain, and dyspnea.
- ◆ **Skin integrity:** Assess for rashes related to treatment as well as fungal infections. Evaluate for ulcers related to lack of activity and loss of weight.
- ◆ **Falls/weakness:** Monitor for fall risk and safety issues. Evaluate for durable medical equipment. Involve physical therapy as appropriate to prevent deconditioning.
- ◆ **Memory loss:** associated with chemotherapy or comorbidities. Use standard tools (MMSE (14), SLUMS (15)) to evaluate and monitor progression of memory loss.

■ Psychological Evaluation:

- ◆ **Anxiety and Depression:** Evaluate regularly. Determine effective coping strategies. Offer counseling and support groups (refer to outside practice if your program does not have this available).
- ◆ **Anticipatory Grief:** May be a significant issue not only for the patient but also for family members and significant others. Involve life review in your visit.

■ Medication reconciliation

- ◆ *Review and determine benefits/burdens of each medication. Discontinue or taper medications that no longer provide any benefit or that may result in more harm due to side effects or interactions with cancer treatment. Involve a pharmacist on your team.*
- ◆ *Review how each medication is dispensed with patient/caregiver. Assess ability to manage medications, and ensure a clear understanding of importance and purpose of each.*
- ◆ *Emphasize consistent round-the clock use of medications to **prevent** symptoms such as pain and nausea. Set up a schedule in the home and educate the family about how to provide support.*

3. Patient goals

- Care plan and patient goals should be reviewed frequently with the patient and caregiver to ensure the appropriate care is being delivered. A more in depth conversation might be required if there is a change in status of the patient to ensure clear understanding of the disease process and the expected trajectory and outcomes.
- Every patient should have an advance directive filled out, preferably a POLST (Physician Orders for Life Sustaining Treatment). Any changes in goals should be promptly reflected in the documents. *These documents should be readily available to the patient, caregiver and paramedics (if called). Many programs have these placed on the refrigerator.*

Depending on the clinical status, options and goals should be readdressed on a regular basis. Informing the patient and the caregiver of options, including hospice, is necessary.

4. Review and education

- Any changes in the treatment plan should be given to the patient and caregiver in writing and reviewed with them during the visit. Include specific instructions regarding a preventive plan, detailing which medical service to call when changes occur or in an emergency. Simple is better! *A good practice is to ask the patient/caregiver to repeat back the changes.*
- Before leaving the patient's residence, patients and/or caregivers should be instructed to call the palliative care service, when available, with any questions or concerns. Ensure they have the number and review the backup plan when the palliative care service is not available.

Ideally, a call to the primary physician/oncologist should be made from the patient's home during every visit and the plan of care should be reviewed.

OPERATIONAL

Patients with complex chronic illnesses require a team approach. Scope of practice of each member of the team should be delineated up front. This includes a clear understanding that optimization of patient care requires that the team function as one. Routine Interdisciplinary Team (IDT) meetings and communication with the other specialists are essential.

Role delineation is vital when working in the home. Prior to launch of the service it is recommended to meet with your primary care colleagues and the Oncology team to establish parameters. Some palliative care medical services co-manage with oncology or primary care, some are purely consultative, and some palliative care services function as the attending provider in the home.

A cohesive relationship with Oncology and Primary care is essential. Care coordination is best accomplished with communication between all specialties. Determining point people in each practice can improve communication channels.

A working relationship with the family/caregivers is critical for success. Strengthening and enabling the patient's support network of family/caregivers will help optimize the patient's quality of life.

Operational policies are required to guide patients in emergencies. A strategy on how to handle emergencies should include provision of a written plan/s. If your service is not 24/7, an off-work hours plan needs to be in place.

Quality data should be collected and reviewed routinely.

- Clinical and operational data, number and length of hospitalizations, patient/family satisfaction and referring entity satisfaction.
- Expected outcomes: improved continuity and quality of care decrease in ER visits and inappropriate hospitalizations, increased adherence to patient goals, improved patient and provider satisfaction.

SUMMARY: LESSONS LEARNED AND BEST PRACTICES

Optimal care requires a well-coordinated team. It is preferable to have a shared electronic medical record to streamline communication.

Frequent team meetings allow other providers to offer insights and techniques. Creativity may be required to develop a successful care plan for complex situations.

Each home setting is unique. Home visits offer insight into the patient's values, barriers, and needs. Figuring out how to eliminate obstacles for patients is critical in order to stabilize the patient's condition and to improve the quality of life for both the patient and the caregiver. Remember that this is the patient's personal space; respect for the home environment is essential.

Focus on maintaining patient's quality of life and meeting patient's individual goals. Although this often includes avoiding inappropriate hospitalizations, some hospitalizations may be necessary to optimize care.

Proactive plans are vital to avoid crises. Use creative solutions with each unique situation.

Active listening provides insight into the patient/caregivers main concerns. It also results in emotional support and creates a trusting relationship.

Efficiencies are obtained through having an adequate number of support staff trained in palliative care to work with the palliative care provider(s). Having support staff who triage phone calls, provide clinical input, assist with care coordination and manage referrals maximizes the efficiency of each provider.

Relationships develop in a different way when in the home; resiliency and self-care must be part of this work.

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