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Chapter

Palliative Care

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Abstract

Palliative care bridges the gap between medically focused care with case management support, and hospice with focus on comfort only in the last 6 months of life. A multidisciplinary palliative team provides support, both medical and psycho-social, regardless of time to end of life. Patients do not forego any treatments or interrupt any current physician relationships when enrolling in palliative care. Programs may be in-patient, clinic based, home based, telehealth or a combination of venues. 24-hour availability is encouraged. Coordination with the existing medical team and the health plan is a key to success. Periodic rounding between the palliative providers and the health plan team facilitates making the managed care system seamless for members and providers. The most common adult diagnosis is cancer, but severe progressive disease of any organ system may be appropriate for referral. Some patients may stabilize or even improve. Pediatric palliative care is somewhat different with the diagnosis more likely being genetic, developmental, or neurologic. Severe diseases in children may be chronic and end of life discussions difficult. Communication skills facilitate advance care planning discussions whether advance directive or POLST. Palliative care is a cost-effective program that improves patient care without the patient relinquishing existing benefits.

Keywords: palliative care, hospice, advance care planning, severe progressive disease, patient support

1. Introduction

Palliative care is a relatively new field that has expanded over the past 15 years. Palliative care uses a specially trained team to support patients with severe progressive disease and their caregivers. The World Health Organization describes palliative care as “... improves the quality of life of patients and that of their families who are facing challenges associated with life-threatening illness, whether physical, psychological, social, or spiritual.” [1]. This includes addressing practical needs and providing bereavement counseling. It offers a support system to help patients live as actively as possible until death.

Palliative care is indicated for a wide range of severe progressive diseases. The most common diseases needing adult palliative care include cardiovascular diseases (38.5%), cancer (34%), chronic respiratory diseases (10.3%), AIDS (5.7%) and diabetes (4.6%) [1]. Other conditions include kidney failure, chronic liver disease, autoimmune diseases, neurological disease, dementia, and congenital anomalies.

Symptoms encountered during palliative care most commonly include pain and difficulty in breathing. Opioids are essential for managing pain and other symptoms. Palliative care is about the quality of living, recognizing that dying is a normal process, and palliative care does not hasten nor postpone death.

A landmark randomized controlled study of patients with metastatic non-small-cell lung cancer demonstrated that the addition of early palliative care, as compared to standard oncologic care alone, not only resulted in less depression, improved quality of life, fewer hospitalizations and emergency department visits, and less aggressive interventions, but the palliative group lived significantly longer [2]. Although this is not meant to imply that palliative care will always prolong life, it does suggest that palliative care certainly does not hasten death.

Palliative care integrates the psychological and spiritual aspects of patient care and offers a support system for the family, the caregivers, and the patients. The patient does not “give up” access to existing providers or any existing benefits including therapies intended to prolong life, such as chemotherapy or radiation therapy, and other disease focused investigations or therapies as well as treating any clinical complications. Palliative care is based on the needs of the patient, not on the patient’s prognosis. It is appropriate at any age and at any stage in a serious illness, and it can be provided along with curative treatment.

2. Defining palliative care versus hospice versus case management versus community care coordination with community health workers (CHW)

For **Palliative Care**, the patient retains all of their disease focused benefits, adding support in addition to disease focused treatments. Palliative care does not require a prognosis shorter than 6 months. Hospice is a program in which the member foregoes curative focused treatment and focuses on comfort only for the hospice diagnosis.

Hospice Care is defined by Medicare as being for the terminally ill (with a life expectancy of 6 months or less) for members having Medicare Part A (Hospital Insurance), for which you accept comfort care (palliative care) instead of care to cure your illness.

Medicare-certified hospice care is usually given in the home or other facility where they live, like a nursing home. Patients can also get hospice care in an inpatient hospice facility if needed. “Original Medicare” will still pay for covered benefits for any health problems that are not part of your terminal illness and related conditions. Once the patient chooses hospice care, the hospice benefit will usually cover everything needed.

Specific for patient’s illness, the hospice team will create a plan of care that can include any or all these services:

- Doctors’ services.
- Nursing and medical services.
- Durable medical equipment for pain relief and symptom management.
- Medical supplies, like bandages or catheters.
- Drugs for pain management.

- Aide and homemaker services.
- Physical therapy services.
- Occupational therapy services.
- Speech-language pathology services.
- Social services.
- Dietary counseling.
- Spiritual and grief counseling for patient and the family.
- Short-term inpatient care for pain and symptom management. This care must be in a Medicare-approved facility, like a hospice facility, hospital, or skilled nursing facility that contracts with the hospice.
- Inpatient care
- Respite care (which is care received in a Medicare-approved facility like an inpatient facility, hospital, or nursing home), so that the usual caregiver (like a family member or friend) can rest. The hospice provider will arrange this for the patient. Respite care givers can stay up to 5 days each time respite care is required. Respite care can be provided more than once, but only on an occasional basis.
- Any other services Medicare covers to manage pain and other symptoms related to the terminal illness and related conditions, as the hospice team recommends.

Initial certification is done by the patient's usual doctor or the hospice doctor. After 6 months, hospice care can be continued provided that the hospice medical director or hospice doctor recertifies (at a face-to-face meeting) that the patient is still terminally ill.

As a hospice patient, the patient always has the right to stop hospice care at any time.

Medicare will not cover any of these once the hospice benefit starts:

- Treatment intended to cure the terminal illness and/or related conditions.
- Prescription drugs to cure the hospice illness (rather than for symptom control or pain relief).
- Care from any hospice provider that wasn't set up by the hospice medical team. However, the patient can still see his/her regular doctor or nurse practitioner if that provider has been chosen to be the attending medical professional who helps supervise the hospice care.
- Room and board. Medicare does not cover room and board for hospice care in your home or if you live in a nursing home or a hospice inpatient facility.

Hospital outpatient care (like in an emergency room), hospital inpatient care, or ambulance transportation must be arranged by your hospice provider unless it is unrelated to your hospice diagnosis.

Case Management is process of assessment, evaluation, care coordination, education, and advocacy to meet an individual's and family's comprehensive health needs. This includes continuity and transition while promoting quality and cost-effective outcomes. Clinical as well as psycho-social issues are addressed. Several types of case management exist:

- Managing patients with high-cost medical conditions. The goal is to coordinate the care to both improve continuity and quality of care while lowering costs.
- Chronic care which may be disease specific
- Catastrophic or large claim management programs
- Maternity case management programs
- Transitional management programs including in-patient discharge planning

The case management team may include

- Nurses
- Physicians
- Social workers
- Pharmacists
- Behavioral health specialists
- Care givers
- Community resources

Another growing trend is the use of **Community Health Workers (CHW)**, non-licensed trusted members of the community, to navigate and assist patients in obtaining community services to address social determinants of health (SDoH) and coordinate with traditional health care. Typical SDoH would include:

- Homelessness/shelter
- Food security
- Safety
- Transportation
- Financial

- Education
- Post incarceration
- Behavioral health
- Adverse childhood experiences

CHW programs are for any patient in need of navigation and support regardless of prognosis or severity of illness. CHWs do not manage symptoms since they are not licensed to provide medical care. Some CHWs may be specially trained to handle advance care planning.

Figure 1 compares case management, palliative care, and hospice.

- Case management: the primary focus is disease focused led by the usual physician driven health care team. Case Manager (CM) and Social Worker (SW) staff assist as needed especially addressing psycho-social needs and coordination of care. These members tend to have catastrophic or chronic illness but are not necessarily nearing the end of life. Although advance directives are encouraged, they are not critical. The patient continues with their existing medical team and retains all existing benefits including disease focused and/or curative treatment.
- Palliative care: although palliative is appropriate at any stage of illness, these patients are usually within their last 1–2 years of life. In addition to their existing health care team, an additional team of physicians, nurses, social workers, and coordinators is added. These patients usually have severe progressive disease. Advance care planning (ACP) is extremely important, and the patient and family should be engaged in this discussion, hopefully with documentation and

CASE MANAGEMENT	PALLIATIVE CARE	HOSPICE BENEFITS
Chronic / complex disease- not contemplating death	End of life 1-2 years and/or chronic / complex disease	End of life 6 months
Concurrent with curative care	Symptom relief concurrent with curative	Symptom relief only NO curative (for terminal illness)
Primary care physician (PCP) and specialist	PCP, specialist, and palliative consultant	Hospice team including physician
Complex Case Management (CCM) RN/social worker (SW)	Integrated team approach MD/NP/RN/SW	Integrated team plus aides, chaplain, and respite benefit
Focus: Curative treatment by usual medical team with support for psycho-social issues	Focus: Transition from curative only to symptom management and goals of care	Focus: Symptom relief by the hospice team with NO curative treatment of the terminal illness
Advance directive +/- Physician Orders for Life-Sustaining Treatment (POLST)	Advance directive POLST discussion	Advance directive and signed POLST

Figure 1.
 Comparison of case management to palliative care to hospice.

distribution of ACP documents. Coordination between the palliative team and the usual medical team is an imperative. The patient is receiving both disease-focused/curative treatment and intensive supportive treatment.

- Hospice: is specifically for those with a prognosis of 6 months or less, although renewals of the 6-month period are possible. The patient is focused on comfort care only for the terminal diagnosis. There is no curative treatment being given. Illness not related to the terminal diagnosis is still treated. Advance care planning with documentation is essential since limiting futile medical care at the end of life is a goal. The hospice team will direct the care of the member unless the patient designates his/her PCP to perform that function. Hospice may be revoked at any time.
- Community Health Workers: are trusted sources of navigators from the local community who are not medically licensed but can assist in addressing social determinants of health (SDOH) needs regardless of the health status. Some CHWs have training in advance care planning discussions. CHWs can be part of the palliative care team.

3. Referral criteria

The most common referral criteria for adult palliative care include

- Severe progressive disease although severe progressive disease can be stabilized or even cured
- Death not unexpected in 1–2 years although predicting the timetable for death may not always be accurate
- Symptoms uncontrolled with the most common symptoms being pain, weakness, shortness of breath, nausea, and depression
- Support needed which includes psycho-social support as well as medical
- Advance care planning (ACP) needed with an advance directive (AD) advisable for everyone and the POLST (Provider Orders for Life Sustaining Treatment) for those nearing end of life (EOL)

4. Models

The most common models used to deliver palliative care include

- Hospital based: A palliative team is available to consult with in-patients and emergency room patients. They may have an out-patient clinic for follow up or they may need to refer to an out-patient program
- Clinic based: the palliative team is able to see the patient in an out-patient clinic.
- Home based; the palliative team is able to see the patient in the home.

- Telehealth: the home visits are virtual using audio-video or audio only. A hybrid model can be used in which the nurse or community health care worker does the home visit and oversees a telehealth visit with a physician, nurse, or social worker.

5. Sources of referrals

Most referrals are made by in-patient case managers, discharge planners, health plan case managers, concurrent review nurses, transition care management nurses, or hospitalists. Other common sources of referrals include primary care physicians, specialty care physicians such as oncologists and nephrologists, or out-patient clinic staff. Although emergency rooms see many palliative candidates, referrals from the ED (emergency department) are less frequent unless special support staff are available to the emergency room for consultation. Data mining looking for high cost and high-risk members through claims data is limited since there is a significant lag time between claims data being processed and the actual sentinel events that indicate the need for palliative support.

Data mining for high-risk members usually requires risk stratification programs such as I Pro (Impact Pro®). A population is stratified from the sickest of the sick down to healthy members. Data mining looks at claims including cost, pharmacy, inpatient utilization, ED utilization, age, sex, diagnosis, demographics, and even social determinants of health. Another tool is the Charlson Co-morbidity Index which looks at multiple co-morbidities to create a score. In any case, prognostication is difficult. Even though these tools may stratify, there is no guarantee that the prediction for any single patient will be correct. Prognosticating the timetable for end of life is even more difficult. Although studies do show the efficacy of palliative care in the last several months of life, predicting when that end-of-life period begins is not always accurate.

The types of patients referred to palliative care may vary and include end-of-life, chronic illness, catastrophic illness, and/or being inpatient. Social determinants of health may also require significant attention. Different illnesses may have different patterns of functional decline (Figure 2). Cancer members may remain quite

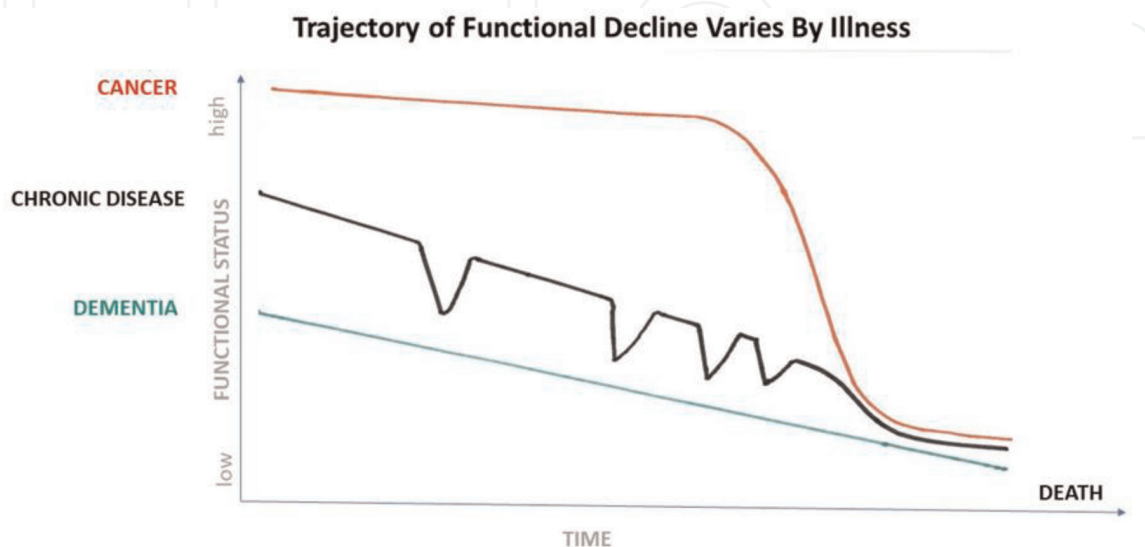


Figure 2.
Trajectory of functional decline variation by type illness.

functional despite significant disease. When the functional decline begins, the rate of decline may be fairly rapid, not allowing much time for interventions at end of life. Chronic diseases such as heart failure may have a slower decline with episodic acute exacerbations. Although they may recover from the exacerbation, they are not recovering back to their previous state of health. The decline is often not noticed since the focus is on the miraculous improvement from of the exacerbation. The exacerbations may increase in frequency and have a slower recovery until the final exacerbation occurs, from which the patient does not recover. The third type of functional decline is exemplified by dementia. In the absence of an acute complication, the course is a slow steady decline which may last for years. These varying scenarios make prognostication difficult.

An interesting tool for prognostication is the “surprise question”. Rather than asking how long a patient is expected to live, the question is “would you be surprised if this patient died within the next 1-2 years?” The efficacy of this tool is debatable and does vary by disease category.

6. Pediatric palliative care

Pediatric palliative care is different than adult palliative in many ways.

- Treating a whole family, including siblings
- Pediatric diagnoses are different (genetic, development, metabolic, neurologic)
- High claims data mining does not always identify candidates (sick neonates are usually the highest cost group)
- Many times, it is catastrophic issues (trauma, burns, complications of appendicitis) that are high-cost severe illnesses in children
- Medicaid high-cost pediatric chronic disease is often carved out to special sick children programs such as CCS (California Children’s Services) in California
- Candidates may be better identified by ICD-10 codes than high cost
- Pediatric diagnoses are often more chronic
- Prognosis determination is difficult in children
- Children have limited skills for verbal expression
- Expressive therapies such as art therapy, music therapy, and play therapy may be used
- Massage therapy can be used for symptom relief
- Hospice and DNR (Do Not Resuscitate) are emotionally difficult decisions in children

Identifying children for referral to palliative care is difficult since they often have disease that is chronic but may have exacerbations for which palliative care is appropriate. The California Department of Health Care Services did define criteria for pediatric palliative for Medicaid members [3]. The criteria were:

- “There is documentation of a life-threatening diagnosis which can include but is not limited to”
 - “Conditions for which curative treatment is possible”
 - “Conditions requiring intensive long-term treatment”
 - “Progressive conditions for which treatment is exclusively palliative”
 - “Conditions involving severe non-progressive disability”
- “The member may continue to access both palliative care and curative care until the condition improves, stabilizes, or results in death.”
- “MCPs [Managed Care Plan] may discontinue palliative care that is no longer medically necessary or no longer reasonable”

7. Structure

The palliative team personnel can vary. Some programs emphasize the physician and nurse practitioner. This is very important in cases in which control of symptoms and disease management are a major factor. In some cases where there is a behavioral health concern or social determinants of health play a major role, the social worker may play the key role. Looking at both health care and social issues, the nurse, either licensed vocational or registered nurse may play the key role. Often the patient will express a preference for nurse or social worker visits rather than physicians and nurse practitioners. For telehealth, having a community health worker may be helpful to assist the patient in setting up a telehealth video visit in the home with the physician or nurse. The approach to staffing may vary depending on other lines of business that the vendor performs. Those vendors who also do hospice may have more physician involvement. Organizations who do home health, may be more nurse centered.

The frequency of visits can be flexible since not every member has the same needs. A “typical” frequency of home visits may be 1 physician/NP visit every 1–2 months, a nurse every week, a social worker once a month, and coordinators and spiritual advisors as needed. These services are supplemented with phone communication. Obviously, not every week would be the same with more visits some weeks and less visits some weeks. If monthly case rates (fixed fee per month) are used, the rate can be adjusted for different levels of care. Those averaging the predetermined number of visits specified in the contract may get paid the full fixed fee per month; but if the average number of visits decreases, the case rate payment can be decreased proportionally. Case rates can also allow fee for service visits above and beyond the case rate services if exceptional services are required. The palliative provider can also work under a fee for service contract. However, the fee for service contract may require more prior authorization or documentation. Case rates can also be adjusted if the

member only was enrolled for part of the month. For in-patient and clinic visits, palliative services are often billed as hospital consults or office visits respectively.

The actual provider of the palliative care, the vendor, has several different models. The payer can contract directly with local vendors. This has the advantage of using vendors known in the community. Depending on the size of the service area, home visits may be relatively easy. Larger national companies can be contracted, but then that company needs to either contract with local vendors or set up a network of employed providers if face to face visits are needed. The use of telehealth with or without community health worker making home visits does allow the palliative provider to cover a much larger service area.

8. Outcomes and disposition

Overall, studies have shown that there is very high satisfaction with home based palliative care programs [4]. In general, utilization of the hospital and emergency department (ED) decrease, overall health care cost decreases (mostly due to in-patient and ED savings), savings are greater when the patient is closer to end of life, and certain diagnoses like cancer are more likely show savings than chronic illness like dementia [5]. Cost reduction does vary by insurance product with largest savings seen in the commercial product, probably because the unit cost is highest compared to Medicare and Medicaid.

Some patients referred to palliative care will choose hospice instead once they understand their options. Of patients qualifying for palliative care, about 15–20% of members will refuse the program. Reasons for refusal include misunderstanding despite explanations, fear that they will receive less care, cultural beliefs, fear of talking about death, family disagreement, or wanting privacy without anyone in their home. Physicians may not make the referral due to a misunderstanding that existing benefits continue, fear that they are giving up, not wanting to discourage the member, or not having the time for a series of end-of-life discussions. Often the physician does not understand the referral process or even the availability of the program.

Patients referred to palliative care may subsequently transfer to hospice, die, move out of the area, change insurance coverage, refuse services after enrollment, or actually improve such that they do not need further palliative care.

9. Advance directives

Advance Care Planning (ACP) is a process of discussing and then documenting a patient's wishes for health care. If the patient becomes incapable of making his/her health care decisions, then two questions arise. First, who can make those decisions for the patient (i.e. who is the patient's legal agent), and second, are the patient's preferences known (and preferably documented)? Part of the discussion is an education of the patient and any family or significant others who the patient may want to be included in this process. The goal is to make informed decisions and then document before a catastrophic event occurs that leaves the patient unable to make their own decisions. Without written preferences, family members may disagree as to what the patient would really want. The patient and family may not understand all of the options. For example, a DNR (do not resuscitate) order may mean do nothing if the heart stops, or do only electrical stimulation, or administer drugs but no chest

compressions. The patient may want CPR (cardio-pulmonary resuscitation) but would not want to remain on a ventilator (breathing machine) if there is no hope of recovery. Decisions could also include feeding tubes, dialysis (artificial kidney), surgery, hospitalization, or certain other treatments. The patient may refuse a certain treatment or agree to a limited trial of a treatment to be discontinued if recovery is not expected. If the directions are not clear, the designated agent would have the authority to intervene and make decisions.

ACP documents fall into two categories. The advance directive (AD) asks the patient to name the person, the agent, who would make medical decisions on their behalf should the patient be unable to do so. This gives the agent Durable Power of Attorney for Health Care. An alternate agent may also be named should the first choice not be available. The AD would also contain a general statement whether the patient's preference is to do anything possible to prolong life, or to limit interventions if there is no hope of recovery or regaining consciousness. A second question is whether the patient wants relief from pain even if it may hasten death. Other requests may be made such as type of burial or religious preferences. The AD can be notarized or signed by two witnesses who are not the agent.

The second document is the POLST (Provider Order for Life Sustaining Treatment). If the state does not allow nurse practitioners or physicians assistants to sign this order, the POLST is referenced as a Physician Order for Life Sustaining Treatment. Some states call this a MOLST (Medical Order for Life Sustaining Treatment). The POLST or MOLST is a specific order signed by the patient or his/her agent, and a physician or nurse practitioner (NP) or physician's assistant (PA) if allowed. The exact form may vary by state, but the content is similar. Does the patient want to be resuscitated? Does the patient not want to be on a ventilator (breathing machine) at all, or only for a limited period? Does the patient not want a feeding tube at all, or just for a limited period? The form also addresses wishes for hospitalization, intravenous fluids, or antibiotics. The POLST or MOLST must be signed by the patient (or his/her agent) and the physician (or NP or PA if allowed).

ACP discussions may require a series of meetings, since there is a lot of education, and the decision making may not be simple. Even if documents are created, periodic review is helpful since the patient's clinical status may change or multiple parties involved may forget what was said. The ACP documents can be revoked or amended at any time. If documents are generated and signed, it is important to distribute the documents to the appropriate parties like the patient, the agent, other participating family members, primary care physician, specialist physicians, and hospitals. For cases closer to the end of life (EOL), a copy of the advance directive may be placed on the refrigerator door in the home so the paramedics would have access to it. Some states have created a registry where the advance directives can be stored for easy access by medical personnel.

The logistics of ACP conversations can vary. The primary care physician or specialist may have the conversation. However, the physician must be willing to devote time to this process including follow up meetings, be familiar with the process, and be willing to initiate what may be perceived as an uncomfortable subject. In the hospital, case managers or social workers may work with the patient and family, but usually when end of life or limiting interventions is the current issue. There are companies who specialize in doing advance directives. Usually, they take a telehealth approach. However, the personnel making the calls may vary between being a physician, a nurse, or a behavioral health trained person. Some community health workers are trained on doing advance directives.

10. Rounding

Communication concerning palliative care patients is critical because most of these patients are quite complex. On the other hand, not everything about a palliative patient can necessarily be addressed at one sitting since there are so many aspects to palliative care that can be discussed. Therefore, the communication or “rounding” has two aspects. One is the structure of the presentation, and the other is the content of the conversation.

The structure of the communication follows the SBAR format. This is a communication method developed in the airline industry to improve communication between pilots and co-pilots to avoid airplane accidents. The technique should shorten the conversation by “getting to the point”. The acronym is:

- **S** is “situation”: a brief description of why we are having this conversation, usually because there is some “problem” we wish to discuss
- **B** is “background”: a brief capsule summary of the historical events that have lead up to this conversation
- **A** is “assessment”: what are the current facts that the caller or presenter has found that should help us solve the problem.
- **R** is “recommendation”: why is the caller calling and what is their recommendation as to what to do

In the medical world, this may be the typical emergency phone call at 3:00 AM from the nurse to the doctor on call. If the conversation goes on for more than 3–5 minutes, the doctor usually interrupts with “why are you calling and what do you want me to do?” This suggests that the nurse is giving too much detail on the background and is not getting to the assessment and recommendation.

An example of SBAR in the world of palliative members for non-emergent presentation (such as nurse to medical director), would be:

S: I have a 63 year old male with hepatocellular cancer complicated by portal vein thrombosis and end stage liver disease with a prognosis 3–6- months.

B: The patient’s course has been complicated by pain, altered mental status due to liver disease, portal vein thrombosis, endocarditis, and a stroke. Lactulose is being titrated for encephalopathy. Morphine is being given for pain. Trans-arterial radio embolization has been used in the past for pain remediation. Patient is on anticoagulation.

A: The patient agrees to a DNR but is not ready for hospice. His vision is failing due to cataracts and he really wants to see the Superbowl. Pain is not well controlled on morphine. Lactulose is effective and diarrhea is minimal. He has a supportive family and wants to be with them as much as possible.

R: We need to evaluate the pain ... repeat radio-embolization is a consideration. The patient states it worked before. The patient wants cataract surgery. We should evaluate him for that. We need a signed POLST for the DNR. Continue the lactulose, morphine, and anticoagulants.

That is a very complicated patient presented in a relatively short-focused format. This allows plenty of time for the physician and nurse to further discuss the nurse recommendations and see if the medical director has any additional recommendations.

Looking at the content presented, the information falls into five categories.

- Medical:
 - Diagnosis
 - Prognosis
 - Symptoms
 - Medications and treatments
 - Current medical team
 - Hospitalizations and ED visits
- Functional status
 - Level
 - Trend
- Support system
 - Family
 - Caregivers
 - Spiritual
- SDoH (Social Determinants of Health)
 - Housing
 - Financial
 - Food security
 - Transportation
 - Safety
 - Behavioral health
- Advance Care Planning (ACP)
 - Advance directive
 - POLST
 - Series of discussions

The key to the conversations with the patient and family is not being judgmental, listening, asking open ended questions, showing empathy, and building a trusting relationship. The patient does have a right to determine how much they want to know, when they want to make their decisions, and what those decisions are.

11. Many faces of palliative care

Case Study 1: 63-year-old with hepatocellular cancer complicated by portal vein thrombosis and end stage liver disease. His prognosis was 3–6- months. The course was further complicated by endocarditis and a stroke. The patient's goal was to see the Super Bowl and he was not ready for hospice. He did agree to a Do Not Resuscitate (DNR) order. He did undergo cataract surgery. Lactulose was adjusted to control hepatic encephalopathy. Due to increasing pain the patient underwent trans-arterial radioembolization (radioactive microspheres injected into the hepatic artery) with improvement. Over 2 years he had 2 emergency admissions and 2 elective admits. Despite his poor prognosis, he survived for 2 years. He did convert to hospice 2 days before his death at home. He did get to see 2 Super Bowls.

This case exemplifies a patient with end stage cancer requiring both supportive and medical care such that he outlived his prognosis and enjoyed a high quality of life despite his diagnosis.

Case Study 2: 54-year-old with an Intracerebral bleed, currently on tracheotomy, ventilator, ventriculoperitoneal (V-P) shunt, and gastrostomy tube (G tube). She is in a long-term care subacute facility and had several acute-stay admits over the past year. She is scheduled for an elective admit for decubitus ulcer surgery. She never regained consciousness during 30-day acute hospitalization. She is full code, divorced with two daughters, ages 18 and 22, and has two siblings out of state. The case was presented to the palliative medical director at rounds, discussed with the subacute attending and case manager, the goals of care were reviewed, and POLST (Provider Orders for Life Sustaining Treatment) discussions were started with family.

The issue was raised why member is full code and whether family is aware that member will not wake up. The family was not aware that member will not wake up. The family expresses the wish to not keep mother alive "like this" recognizing the that decubitus ulcers can be painful.

The subacute attending concurred with decision to discontinue the ventilator. Palliative care arranges to discontinue vent with a palliative case manager, social worker, and spiritual advisor present. Time was allowed for the out of state relatives to join the daughters to be present when the ventilator was discontinued.

This is a case of palliative care addressing end of life wishes, advance care planning, and avoiding futile medical care.

Case Study 3: A 45-year-old presented with multiple emergency visits and admissions for abdominal wall infection. Five months prior, the member had undergone an abdominal hernia repair with placement of a mesh into the abdominal wall. The patient is having ED or acute admits 1–2 times per month. The member has abdominal pain and infection of an open wound at the hernia repair site. Oxycodone has been prescribed fairly regularly along with frequent antibiotics.

The member has filled all prescriptions for antibiotics and kept follow-up appointments with her surgeon and PCP. The surgeon was consulted as to why the mesh, the foreign material in the wound, has not been removed. The surgeon agrees that

removal of the mesh is indicated, but he feels the surgery is too difficult for him to do due to obesity and scar tissue. The palliative team contacted a university-associated bariatric surgeon who agreed to do surgery, which was successful, and the wound healed. The course has been complicated by clostridium difficile, recurrent diarrhea, intermittent nausea and vomiting, and depression but with only occasional emergency department visits or admits.

This case seems to be a patient with severe progressive disease, but it is curable disease if the medical condition is treated properly. In this case the key intervention by the palliative team was to make the appropriate specialist referral.

Case Study 4: 65 year old, homeless patient with severe COPD requiring intermittent oxygen, continues smoking, and with multiple visits to the ED and hospital is referred to palliative care.

He had lost his job as a caretaker about 6 months prior. He now lives in his Lincoln Navigator SUV and he likes living there. He has portable oxygen and still smokes. He goes to senior centers for warmth, food, and socialization. He keeps some PCP (primary care physician) appointments at an FQHC (Federally Qualified Health Center) and intermittently attends AA (Alcoholics Anonymous) meetings. The palliative assessment was that the member needs structure and support. He does need regular PCP visits. Ideally, he should stop smoking and get permanent housing, but member not currently interested.

The palliative team arranged weekly visits at his car, at a senior center, or at other designated area. Phone call reminders were a key to providing structure and support. He was reminded of PCP appointments and to take his meds. His Friday “tuck in call” avoided weekend emergencies. The team continued discussion of housing and smoking and maintained phone contact.

No hospitalizations or ED visits occurred over 10 months. The patient is willing to talk to someone about permanent housing.

This case emphasizes the value of addressing social determinants of health through support and structure. Coming to the patient, gaining his trust, and being creative in providing support far outweighed the effect of the medical interventions.

12. Bad news conversations

Delivering bad news or discussing end of life issues is not always a pleasant event. The most common barriers to delivering bad news is:

- Fear of causing emotional harm to the patient
- Fear of taking away “hope”
- Focusing away from “cure” is perceived as failure
- No one taught us about this in medical or nursing school
- Bad news discussions take time
- The initial response may not be pleasant

Proceeding with planning cannot occur until you get through the emotions:

- It takes time, often more than one conversation
- There's lots of questions and explanations
- The medical plan needs to be coordinated with the medical team
- The support plan may require an extra layer of support from a multidisciplinary team
- Ongoing re-evaluations are frequent
- Knowledge helps overcome fear

Although no one likes to deliver bad news, it is an essential component of quality medical care and may be the most remembered event by the patient and family. You cannot proceed with planning unless your patient has been informed.

- You cannot make bad news good
- Bad news may be seen differently by the deliverer and the recipient ... there is medical reality and there is patient expectation
- The initial reaction to bad news may not be pleasant e.g. anger, denial, depression, blame
- Addressing bad news is essential to doing realistic planning: medical as well as emotional, spiritual, and supportive.
- Ask how much detail the recipient would like
- Respect cultural preferences and social disparities
- Patients and families do have a right to meaningful informed consent

Show your concern:

- Right setting- private
- Right participants- decision makers
- No interruptions
- Eye level conversation

Basic techniques for the Bad News Conversation (Adapted from Baile, Buckman, Lenzi, et al., *The Oncologist*, 2000; 5: 302).

Validation- we respect your feelings.

“Many other patients have had similar experiences”
“I can understand how you felt that way”

“You were correct to feel that way”

Empathy- we care

“I’m sorry to have to tell you this”

“This is difficult for me”

“I can see how upsetting this is to you”

Probe further- we need to talk more

“Tell me more about it”

“Could you explain what you mean”

“Could you tell me what you are worried about”

Ask the patient to summarize what they heard.

Discuss next steps and follow up.

13. Helpful hints

Acceptance of palliative care has been a slow process. It can be time consuming and uncomfortable, despite its benefits. Some of the key factors in having a successful program include:

- Communication and coordination: Palliative care patients have all their usual health benefits plus the palliative team. They may also have a managed care health plan. All these entities must coordinate their efforts to care for this vulnerable population.
- Patient participation: Severe progressive disease is both a physical burden and an emotional burden. The patients’ wishes must be respected, regardless of our own personal opinions. We want to listen to the patient and help them to express their preferences.
- Family consensus: Disagreements among family members can be another barrier to good decision making. Everyone should try to respect the patient’s choices. The goal of the Advance Directive is to designate the agent who would have the final say if the patient cannot make his/her decision. Cultural factors should be respected.
- 24 phone access to palliative providers: Most palliative providers can take phone calls or do interventions after working hours. This facilitates interventions that can prevent hospitalizations or emergency room visits.
- Health plan contacts (as problem solvers, hands on, real time): The palliative team and the medical team may not be able to navigate the health plan system. The health plan needs to have live personnel to assist those teams on benefit related issues, identifying contracted providers, or issues requiring prior authorization.

- Compassion, Open Mind, Listen: Severe progressive disease and/or end of life are emotional times. We must always try to put ourselves in the shoes of our patients to give them the most effective and empathetic support that we can.
- Not always successful: Palliative interventions are not always successful. We can try to do our best, but outcomes can vary despite the best care.
- Community support: Patients may need support from community-based organizations. The palliative team can navigate patients to community resources, provided that those services exist and have been identified. We may successfully navigate the patient to what they need, but if that resource does not exist we have just “navigated them to nowhere.”

14. The elevator speech

Trying to explain palliative care to someone within one to two minutes may not be easy, but here is an elevator speech. The two versions are similar, but one is written in prose, and one is in bullet point format. There are some variations between different palliative programs. The health plan may or may not provide a palliative care benefit. The program may or may not be offered at no cost. The health plan may or may not require prior authorization. The plan may or may not have its own palliative team to review referrals and serve as a liaison between the referring party, the palliative provider, and the patient. The referring party may have contact directly with the actual palliative provider. Not all palliative teams provide phone access or emergency service after hours.

Version 1: Palliative care is a service which may be provided by your insurance company usually at no cost to the member or doctor (check this since palliative care may or may not be a benefit). A team of physicians, nurses, social workers, and coordinators provide an extra layer of support to your members with severe progressive disease in need of symptom control, advance care planning, or psychosocial support. These are members who are frequently in the hospital or emergency room. The member retains all their normal health plan benefits which are coordinated between the doctors, the medical group, the health plan, and the palliative care provider. The palliative care providers usually have an after- hours call line (check this since some palliative care providers may not have an after- hours call line or provide services after-hours) and can provide services after hours. To make a referral, just complete the referral form, and fax or e-mail it to the health plan or palliative provider (the insurer may require prior authorization). For questions, just call the health plan palliative team (check that the plan does have its own palliative team). A contact list and referral form is attached. All referrals will be reviewed by health plan palliative medical directors. Palliative care is a program for the living ... to provide the highest quality of life despite serious illness. Please remember that palliative care is not hospice. With palliative care the member may continue their disease focused treatment and there is no 6-month limitation. The palliative program has improved members' quality of life and reduced their usage of the hospital and emergency department to manage their illness. Our members and our doctors appreciate the extra layer of support that has been coordinated for them.

Version 2: Elevator speech in bullet point format.

- Our palliative care program is a home-based palliative care program (check if the program is either a clinic-based program or a telehealth program rather than home based.)
- Members are often scared off by the term “palliative care” because they confuse it with hospice
- Palliative care is NOT hospice: Palliative care is not just end of life, it does not have a 6- month limitation, the member retains all their health plan benefits, and members may continue with all their disease focused treatments while on their palliative care program
- Palliative care is for the living
- The member retains their PCP, their specialists, and their medical group.
- The health plan has a team of nurses who screen the referrals and assist in coordinating care (check that the health plan does have contacts who review referrals)
- Referrals can be made by sending a referral form to or calling the health plan
- The palliative care program (check this since palliative care may or may not be a benefit) is at no cost to the member or medical group or doctors
- Referrals must be approved by the health plan (check if this is a requirement)
- Criteria for referral include members with severe and progressive disease, in need of symptom control, advance care planning, or psycho-social support.

15. Final thoughts

“You can’t control the wind, but you can adjust your sails.” Yiddish Proverb

“Life is like riding a bicycle. To keep your balance, you must keep moving.” Albert Einstein.

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