

Group assignments, NSCPM Module 1

Monday 23 September 2019, morning

A Below you will find the two most widely used definitions of palliative care.

Discuss similarities and differences between the two definitions.

In your opinion, what are the strengths and weaknesses of each definition?

Which definition do you prefer, and why?

Palliative care is the active, total care of the patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms, and of social, psychological and spiritual problems is paramount. Palliative care is interdisciplinary in its approach and encompasses the patient, the family and the community in its scope. In a sense, palliative care is to offer the most basic concept of care – that of providing for the needs of the patient wherever he or she is cared for, either at home or in the hospital. Palliative care affirms life and regards dying as a normal process; it neither hastens nor postpones death. It sets out to preserve the best possible quality of life until death. (EAPC 1998)

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 impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. (WHO 2002)

B How can a palliative care population be defined? Try to agree on the most relevant variables to describe a palliative care population. Examples of variables could be age, diagnosis, life expectancy etc.

C Outcome is defined as ‘a change in health status or quality of life that can be attributed to health care’. Outcome measurement involves the use of a measure to establish a patient’s baseline health status, and then evaluating changes over time against that baseline.

Why is outcome measurement more challenging in palliative care than in many other areas of health care?

D You have already discussed two definitions of palliative care. Based on these definitions and your own experiences and reflections, what are the core values of palliative care?

How are these values manifested in the palliative care service in which you work?

E Why did you choose to work in palliative care? This is a mostly a question for self-reflection, but you may share your thoughts in the group if you want to.

What do you hope to get from the Nordic course?

Monday afternoon, 23 September

Please discuss these scenarios, define one or more relevant research questions, and suggest one or more approaches for a course project to answer the question(s).

1. Two years ago, ESAS was implemented in three advanced home care units in a Swedish county. At present only one of the units is still using the tool. The responsible physician is eager to know why implementation was successful in one unit and not the others, and how she should go about to have the tool implemented in the other two locations.

2. You work in a comprehensive hospital-based palliative care centre consisting of an ambulatory team, an inpatient unit, an out-patient clinic, and a day care centre. During the last couple of years it has been increasingly difficult to recruit patients to the day care centre. You want to explore this situation and find out how more patients can benefit from this service.

3. One of your colleagues works in a palliative care team in a hospital in a rural area. One day he experiences a difficult situation treating a terminally ill patient with an ICD (implantable cardioverter-defibrillator). No plans had been made for deactivation of the ICD.

Your colleague wants his hospital to be better prepared for the next dying patient having an ICD. He thinks this will be a nice project for the Nordic course. How should he go about it?

4. An oncologist with a special interest in palliative care has been admitted to the Nordic course. She has the clear impression that while physical and psychological symptoms are reasonably well addressed in her department, the patients do not receive adequate spiritual care. Suggest a course project to address this assumption.

5. Your special interest is cancer pain management. Working as a palliative care consultant in a university hospital, you have the clear impression that less epidural catheters have been inserted during the last two years, compared to the years before. Is this a coincidence, or has there been a change in policy? How can you find out?

6. As a consultant in a hospital-based palliative care team you attend the EAPC congress and read a poster presenting somatostatin (octreotide) as a treatment for refractory chemotherapy-induced diarrhoea. You wonder whether you should try this treatment in your own hospital. Give an idea for a course project addressing this issue.

7. During a meeting for palliative care physicians in a region in one of the Nordic countries, it became evident that the doctors prescribed corticosteroids very differently. They did not use the same doses, and not even the same drugs. One of the younger physicians thinks this is very strange - how can he know how he himself should prescribe these drugs? Give some ideas for projects to explore this situation and help your young colleague.

8. A physician has just been accepted to the 8th NSCPM. She has no research experience and is not tempted by statistics and large databases. Her interests are more in the field of arts and crafts. Give her some suggestions for a course project that could fit her inclinations.

Group work, Assessment, Tuesday morning 24 September

1. Assessment should be an ongoing process throughout the course of a patient's illness. Please list some key points in the patient pathway where you would recommend a structured, holistic assessment to be undertaken.
2. Who should undertake the assessment?
3. Discuss in the group each of the quotes below, using the following questions as a guide:
 - Do you agree or disagree with the statements?
 - How do you handle each aspect at your work place and in your daily work?
 - Are you satisfied with your way of doing things – why, or why not?

“The patient is at the heart of assessment and care planning. The process of assessment should be one of partnership between patient and professional. Assessment should be patient “concerns-led”, and helping patients to assess their own needs should be central to the process. The assessment should largely follow a conversational style.”

“Self-assessment is a useful way to identify issues of particular concern to the patient, for subsequent discussion with the assessor. Patients should therefore be offered the opportunity to self-assess. Self-assessment is widely seen as acceptable for many aspects of the physical and social and occupation well-being domains. Caution should be exercised in relation to the psychological well-being and not pursued in relation to the spiritual well-being domain, the latter in particular does not lend itself to self-assessment.”

“Assessment should take no more than 30 minutes on average.”

“There is no proforma or “tool” designed for the holistic assessment of palliative care needs for adults with cancer. Health care teams may wish to utilise one or more existing tools as part of a holistic assessment; however, in all cases it must be ensured that the assessment covers the full range of needs.”

4. Which assessment tools do you use routinely? How do you judge their usefulness?

Case discussions, Tuesday September 24

Case 1

Anne is 50 years old, and she has breast cancer with skeletal metastases. She has received palliative radiotherapy with some effect, and she is still receiving systemic tumor-directed therapy stabilizing her disease.

Due to back pain she is currently on oral morphine, sustained release, 40 mg/24h. Her background pain is “controlled”, but she is experiencing constipation.

Q1: How will you approach the problem?

The standard treatment had insufficient effect.

Q2: Which are your considerations for intensification of the treatment of opioid-induced bowel dysfunction?

Case 2

Peter is 76 years old, has pancreatic cancer with abdominal carcinomatosis. Further chemotherapy or surgery are not realistic options.

Q3: Which items will be important to discuss in the care process?

Peter states that he wants “comfort care”, and you reply that you will offer the best possible palliative care.

Q4: Are the two terms equal?

Case 3

During their disease trajectories, both Anne and Peter suffer severe pneumonia.

Q4: Reflect on if and how you will think differently on antibiotic treatment?

Q5: Antibiotics at the end of life: Will it prolong life? Will it improve symptom control? Or is it non-beneficial?

Case 4

Jan is recently retired and was admitted to your hospital due to a cerebral stroke, but he can still drink fluids and take medication orally. From his previous medical record is reported a peptic ulcer and gastro intestinal reflux. A recent CT revealed a dilated thoracic aorta, but also an advanced malignancy in Jan’s upper abdomen. The malignancy is so far not further diagnosed. You are called upon because you are the expert on symptom management.

Q6: Jan suffers from singultus (hiccups). How can you help him?

Case 5

Just before her 49th birthday, Jennifer was admitted to hospital two years after surgery for colon cancer. Prior to admission she experienced vomiting and abdominal distension and cramps. Jennifer is one of your friends, and she thinks highly of your medical skills. Awaiting an initial CT scan, she calls you and asks: Q7: Has my cancer relapsed?

Q7: What is the purpose of the initial diagnostic work-up?

The results from the CT showed probably two stenotic parts of the small intestine, and a small amount of ascites.

Q8: Please reflect on the current situation and possible treatment options.

Surgery was performed and Jennifer was at relatively good health for several years. After a long period of chemotherapy her abdominal pain increased, she lost weight and had to stay in bed for more than half of the day. When her abdominal distention increased, her urine seemed very concentrated, and she had no bowel movement for six days, she was admitted to hospital.

After a new CT scan, the physician sat down by her bed and started: "I am afraid I have some bad news".

Q9: Given the clinical information, what are plausible scenarios for the extent of the disease?

No further surgery was possible.

Q10: What are the relevant medical treatment options for malignant bowel obstruction?

Case discussions Thursday afternoon 26 September

Case 1: Advanced cancer - cognitively impaired patient

Hannah is a 70-year-old woman with a prior history of elevated blood pressure, arthrosis. Smoker.

Her general practitioner had recently referred her to a neurologist because of disorientation (self-reported), dizziness and loss of balance. She was waiting for a head MRI when she was hospitalized because of disorientation, headache and vomiting.

Head CT showed multiple metastatic masses in her brain, and from chest x-ray a lung tumor was suspected and later confirmed by CT which also revealed masses in the mediastinum, near kidneys and in several bones.

She was started on dexamethasone and oxycodone and received a dose of denosumab, then transferred to a palliative unit/nursing home.

Q1: Would you consider other treatment options for Hannah? Give pros and cons for a more extensive palliative treatment plan.

At first evaluation in nursing home she was a bit disoriented and had some memory loss. You suspect an underlying dementia (Alzheimer type, moderate at least) from information gathered.

Q2: How does a cognitive impairment affect your palliative treatment plan for Hannah?

She needed very little medication for pain or shortness of breath during the first month or so. Dexamethasone was lowered and a second dose of denosumab was given 4 weeks after the first.

She did learn to remember her diagnosis but would often forget it at times and was mainly happy to be around other inhabitants and staff. We established a rule not to remind her when not necessary, because she would grow anxious and require someone to sit with her for long periods of time. She did not receive medication for anxiety at this time.

After a month's time she started to feel out of breath and received inhalations of salbutamol and ipratropiumbromide and depot oxycodone. After a week she was unable to breathe freely despite this and had received over 100 mg of oxycodone in the preceding 24h hour period.

Dexamethasone was started again together with SC infusion of morphine, haloperidol, lorazepam and glycopyrronium - basal infusion plus bolus. This eased her symptoms and sedated her sufficiently to relieve her suffering. She died in the nursing home the next week.

Q3: How do you use opioids and steroids for dyspnea? Any special considerations with a cognitive impaired patient? Starting doses, dose escalations?

Q4: Are there other palliative treatment options you would consider in this setting?

Q5: Is this last step of medication palliative sedation? What do you consider to be palliative sedation and what is your experience with palliative sedation?

Case 2: Malignant bowel obstruction

60 years old Karen was in 2017 diagnosed with advanced ovarian cancer. She initially received palliative chemotherapy (6 series of carboplatin). Later, after progression, she received radiotherapy 30 Gy x 10 (uterus and ovarii bilateral).

A few months later she was hospitalised with epigastric pain, nausea, vomiting and constipation. A CT scan showed ileus + peritoneal carcinomatosis.

She was conservatively treated with intravenous fluid, nasogastric tube, steroids, laxatives and ascites drainage. The outcome was successful with a resolved ileus.

Second line chemotherapy was started (Caelyx).

Over the next months she had several readmissions to the hospital with a similar symptom picture of sub-ileus and also a high CRP 305, hypoalbuminemia 24, and epigastric pain. A gastroscopy showed oesophagitis and stomach retention.

She refused to have a nasogastric tube.

She gradually got more tired - sleeping most of the day, sometimes confused. She experienced anxiety primarily during the night. No stools, nausea.

Q1: How do you treat a sub-ileus episode – nausea, vomiting, constipation, stomach pain?

Q2: When do you try to re-establish passage of stools with laxatives and other medication that stimulate peristalsis? When do you start an “ileus-pump”?

Q3: What can you do to plan ahead for a patient with high chance of relapsing symptoms and readmissions.

Q4: The gynaecologist is unsure about continuing chemotherapy. What is your point of view?

Q5: Would you at some point start this patient on parenteral nutrition? Give reasons for your choice.

Case 3: advanced pain treatment, palliative sedation

59-year-old Jenny was diagnosed with stadium IIB cervical cancer, squamous cell carcinoma, in March 2017 and first treated with external and intracavitary radiation therapy.

Sadly, her disease relapsed and later progressed despite 2 lines of chemotherapy and also off-label immunotherapy. CT scans showed enlarged pelvic lymph nodes, a tumor deposit near the rectum, and also near the ileocecal mesenteric flexure, in the wall of the sigmoid colon. There was also left kidney hydronephrosis which was relieved with a JJ-stent

In August 2018 she had a small bowel obstruction, and a loop ileostomy was established.

She was referred to the local palliative care clinic in late August 2018. At this point the ureteral stent (JJ stent) had been replaced a few times, she had been treated for many life-threatening infections, and she had been diagnosed as a carrier of ESBL in ascites. At this time, she received parenteral nutrition. To relieve her pain, she was treated with first SC then, due to edema, IV oxycodone.

In October 2018 she received an intrathecal catheter which had to be replaced several times due to occlusions.

The patient was admitted to the palliative care unit January 26th, 2019. At this point she received intraspinal bupivacaine (Marcain), fentanyl and clonidine as well as intravenous hydromorphone (Palladon), eskatamin (Ketanest) and midazolam. She also received paracetamol and dexamethason intravenously.

Because of chronic infection related to tumor in the pelvic areas with connecting fistulas she was, and had been, treated with intravenous meropenem, a broad-spectrum carbapenem antibiotic drug since December 2018. Meropenem had been stopped on two occasions, but the result was an increase of symptoms of fever and pain.

Q1: What is your experience with advanced pain treatment. What do you do when “everything fails”?

Q2: What “level” of advanced symptom treatment is possible and realistic to offer your patients at hospital and at home. Any differences between countries and regions?

Q3: What are your thoughts on the use of broad-spectrum antibiotics in this setting?

The patient’s daily activity was severely decreased. She was unconscious/asleep for the majority of the day, but when awake, she was still in pain and overwhelmed with anxiety, which also caused stress and tension on her family. She had severe edema from her extremities all the way to her armpits/axilla. In the timespan of a few hours January 30th she received 125mg hydromorphone as

IV bolus combined with large amounts of diazepam IV. She also received increased amounts of medications via her continuous IV and intraspinal pumps. The situation clearly was intolerable both for the patient and family, but also for the medical staff. A joint agreement was made on February 2nd which said that if the situation did not better itself, the patient would be put under general anesthesia with Propofol.

In a situation that could be described as desperation to relieve pain the patient was administered unconcentrated bupivacaine (Marcain) intraspinally February 4th. The treatment had some effect on the patient's pain, but it had to be administered with the patient lying flat/supine. The patient expressed strong anxiety and breathlessness during the administration and treatment, and it had to be abandoned. The dosing of continuous intravenous Midazolam was increased rapidly without effect. 10->20->40mg/24h.

Dexdor (dexmedetomidine) was then introduced on February 5th. The patient was started with a continuous intravenous infusion of 0,7mcg/kg/hr., with a plan to increase dose with 0,3mcg/kg/hr every 30 min if needed. A maximum dosage of 2mcg/kg/hr. was set.

She was still in need of continuous subcutaneous and intravenous medication for pain and anxiety, but she remained calm and if not symptom-free, then at least with what appeared to be a tolerable symptom control.

The patient and her partner got married while admitted to the palliative care unit February 16th. The next day her situation worsened. She became delirious and received increased amounts of dexmedetomidine the next few days. She was asleep/unconscious for the majority of the day, and received a dosing of dexmedetomidine of around 2,0mcg/kg/hr almost continuously. Dexmedetomidine was reduced once daily in order to wake the patient. When awake, the patient was still delirious, and the practice was abandoned. All medications except continuous intravenous and intraspinal infusions combined with dexmedetomidine and furosemide was discontinued from February 19th. The patient died on February 23th.

Q4: What options do you consider before deciding on palliative sedation? And how do you make this decision?

Q5: Do you in your practice have guidelines to support your decision and a procedure regarding palliative sedation?

Q6: Is this an imminently dying patient? If not, how does it affect your treatment choices?

Q7: When would you stop IV antibiotics and parenteral nutrition?

Q8: Should her saturation, heartrate, respiration, blood pressure and so on be measured and how often? Is this an ICU patient?

Q9: What are your drugs of first choice for terminal/palliative sedation? Should drugs like propofol and dexmedetomidine have a place outside the ICU/in a specialist palliative care setting?

Case 4: Blood transfusions for symptom control

Marc is an 80-year-old man who lives with his wife who has Alzheimer. He has COPD, claudication, and cardiac failure NYHA 2. He smokes.

He was diagnosed with prostatic cancer with skeletal metastasis at time of diagnosis in 2012. PSA 370 mcg/L. He was initially treated with a GNRH analogue, from 2014 bicalutamide adjuvance. During 2015-16 Xtandi and Xofigo is tried by the oncologist. PSA 99 mcg/l in March 2018, PSA 278 mcg/L in July 2018, PSA 455 and 560 mcg/L in August 2018 when active treatment is interrupted due to confusion and deranged electrolytes.

His general status stabilized with daily help from home care nurses.

In October 2018 his hemoglobin drops to 83 g/L and a blood transfusion at home is organized after which his energy level is increased.

Since his first transfusion he has received blood-transfusion approximately once a month, when hemoglobin level drops below 90 g/L, including the week before celebrating his 80th birthday in May with a weekend away together with his family.

After transfusion he resumes his daily walks and has lunch at the restaurant in the village. His palliative team plans to continue with the transfusions as long as his quality of life improves from transfusion, and the frequency keeps at 3-4 weeks.

Q1: What are indications for blood transfusions in different palliative settings? Do you have one or more hemoglobulin cut-off levels for transfusion in these settings?

Q2: Do you have guidelines to help with your decision?

Q3: How do you evaluate the effect, and what should the effect be for you to continue the treatment with transfusions?

Q4: Is blood-transfusion at home an option in the area you work?

Q5: Any thoughts on cost-benefit of blood transfusions in this and similar settings?

Case 5: Repeating nausea in a patient with pancreatic cancer

60-year-old Pia was after a period of nausea and vomiting diagnosed with pancreatic cancer. CT scan showed compression to the superior mesenteric vein and common bile duct. The laboratory tests demonstrated elevated bilirubin and liver transaminases. Pia's nausea improved when she got a PTC-drain. Treatment plans were made with neoadjuvant chemotherapy and surgery.

She started at diagnosis with parenteral nutritional support 995kcal/day.

Q1: Discuss the pros and cons of starting parenteral nutrition in this patient. Will the patient benefit?

Several weeks after she had started parenteral nutrition 1250ml (995kcal), it was changed to 1875ml (1910 kcal) because of bad appetite and weight loss.

The patient had severe nausea again and the oncologist paused chemotherapy and made a referral to the palliative team for help.

Q2: What could be causing nausea in a patient with pancreatic cancer? Give a couple of suggestions before continuing reading this case. See if you can cover most of the several reasons this patient experienced nausea in her following case history

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The nausea responded to short treatment with metoclopramide and stopped when the nutritional support was changed back to 995kcal.

A few weeks later she had nausea again. At the time she had a Candida infection in the oral cavity. After treatment with nystatin the nausea stopped.

About three months after the patient's diagnosis she was hospitalized with an infection. She was discharged with Metronidazole and TMT-Sulfamethoxazole tablets with increasing nausea following.

When Pia had finished the neoadjuvant therapy, her nausea increased while waiting for CT scan results. Oxacepam tablets relieved her nausea in this time period.

A few days after pancreatectomy, Pia again had nausea and vomiting, and CT scans showed an ileus which later resolved with a conservative approach. Haloperidol relieved her nausea during that period.