Palliative Care Outcomes Collaboration in Ireland (PCOCI)

Sample Cases with scoring of PCOC Tools *and* PCOC Self-test Questions

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Please note: The cases and questions outlined in this document are fictional and for educational purposes only.

Any similarity to a real case is purely coincidental. Names have been randomly chosen.

PCOC
palliative care outcomes collaboration

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CASE 1:

Situation: John was a 56-year-old gentleman admitted to the Inpatient Unit (IPU) for symptom management.

Background: History of gastric cancer with pancreatic metastasis. Married with four children in their twenties.

Assessment: John described the feeling of food getting stuck in his oesophagus and post-prandial vomiting. Reflux was also an issue and John was experiencing moderate nausea and abdominal pain. John was moderately distressed and anxious about his family. His wife was very distressed but declined to talk to staff. John required one person to assist him for toileting, moving in bed and mobilising. Independent with eating, although only consuming small amounts.

PCOC Tools:

Phase:

Unstable (as no plan of care currently in place to deal with symptoms and family distress was high)

RUG-ADL:

Bed mobility: score 3,

Toileting: score 3,

Transfers: score 3,

Eating: Score 1,

Total score 10/18.

Problem Severity Score:

Pain score 2,

Other symptoms score 2,

Psychological distress score 2,

Family distress score 3,

Total Score 9/12.

AKPS:

60% as he needs some assistance

SAS:

This is scored by the patient where possible, scoring is from 0-10, but can be clinician or family rated.

- Distress from difficulty sleeping 3/10,
- Distress from appetite 7/10,
- Distress from nausea 9/10,
- Distress from Bowels 8/10,
- Distress from breathing 0/10,
- Distress from fatigue 7/10,
- Distress from pain 7/10.

In response to this:

John was reviewed by the medical and nursing teams and a plan of care put in place.

He was commenced on a syringe driver to control his pain and nausea. Although symptoms improved, he still required breakthrough medication for mild pain and nausea.

John and his family had input from the nursing, medical and social work team in order to support them and their distress reduced considerably, although his wife remained distant.

His functional capacity remained the same.

The following morning:

Re-scoring the PCOC Tools:

Phase:

Stable (as a plan of care was in place and although symptoms were not totally controlled the symptoms he had were anticipated and medication intervention was ongoing and planned)

RUG-ADL:

10/18

Problem Severity Score:

Pain score 1,

Other symptoms score 1,

Psychological distress score 1,

Family distress score 1,

Total Score 4/12.

AKPS:

Remains at 60%

SAS:

Remains patient-rated where possible.

- Distress from difficulty sleeping 3/10,
- Appetite 9/10,
- Nausea 3/10,
- Bowels 4/10,
- Breathing 0/10,
- Fatigue 7/10,
- Pain 3/10.

One week later:

John was experiencing moderate abdominal pain and distension, moderate nausea and some reflux.

His overall functional status was declining, and he now required a hoist transfer for toileting and to sit in the recliner chair. He spent much of the day in bed as fatigue was severe.

His oral intake was nil at this stage.

John was accepting of his illness and was content to speak openly and frankly about his illness. John was at peace, but his wife and family were becoming more distressed at John's weakening condition and required more support.

On rescoring the PCOC Tools:

Phase:

Deteriorating (as John's overall functional status was declining, there was a worsening of existing problems and his family experienced an increase in their distress)

RUG-ADL:

Bed Mobility: 5,

Toileting: 5,

Transfers: 5,

Eating: 3,

Total Score 18/18.

Problem Severity Score:

Pain: 2,

Other symptoms: 3,

Psychological distress: 0,

Family distress: 2,

Total Score 7/12.

AKPS:

40% (as John was in bed more than 50% of the time)

SAS:

Again patient-rated where possible.

- Distress from difficulty sleeping 4/10,
- Appetite 9/10,
- Nausea 7/10,
- Bowels 2/10,
- Breathing 1/10,
- Fatigue 9/10,
- Pain 6/10.

Later that week John became less responsive, his breathing was fast with some apnoeic episodes. His symptoms were controlled, and his family were updated about his condition but were very distressed at this stage. He was bedbound requiring full nursing care.

On re-scoring the PCOC Tools:

(proxy scored at this stage)

Phase:

Terminal (death was likely within days)

RUG-ADL:

Remains at 18/18

Problem Severity Score:

Pain: 0,

Other symptoms: 1 (for tachypnoea),

Psychological distress: 0,

Family distress: 3,

Total Score 4/12.

AKPS:

20%

SAS:

Would have to be clinician or family rated at this stage.

- Distress from difficulty sleeping 0/10,
- Appetite 0/10,
- Nausea 0/10,
- Bowels 1/10,
- Breathing 7/10,
- Fatigue 4/10,
- Pain 3/10.

John settled and remained peaceful until he died with his family present.

CASE 2:

Situation: Sarah was a 67-year-old lady who was admitted to the IPU for symptom management.

Background: History of ovarian cancer, peritoneal and liver metastasis. Married to Paul with two grown up children living abroad.

Assessment: On admission Sarah had severe nausea and vomiting, much worse in recent days. Her abdomen was very distended and uncomfortable from ascites. She had bilateral leg oedema and found mobilising difficult. Her meals had to be small due to poor gastric motility and ascites. Abdominal and leg pain were severe at times and she suffered from moderate fatigue. Functionally she required minimal assistance of one person for all ADL's and the use of her zimmer frame for mobilising. Psychologically, both Sarah and Paul were very positive and stated that their children were fully aware of Sarah's condition.

PCOC Tools:

Phase:

Unstable (as no care plan currently in place to control Sarah's symptoms which were severe in nature and there had been a rapid increase in the severity of symptoms in the last few days prior to admission)

RUG-ADL:

Bed mobility: 3,

Toileting: 4,

Transfers: 4,

Eating: 1,

Total score 12/18.

Problem Severity Score:

Pain: 3,

Other symptoms: 2,

Psychological distress: 0,

Family distress: 0,

Total Score 5/12.

AKPS:

60%

SAS:

This is scored by the patient where possible.

- Distress from difficulty sleeping 2/10,
- Distress from appetite 1/10,
- Distress from nausea 9/10,
- Distress from bowels 3/10,
- Distress from breathing 8/10,
- Distress from fatigue 6/10,
- Distress from pain 9/10.

Three days later Sarah reported crampy abdominal pain which could be severe in nature and was different to the previous abdominal pain. Her bowels had not opened in three days and on examination by the medical team bowel sounds were high pitched and tinkling. Nausea was also more of a feature on this day, moderate in nature.

Functionally, due to increased abdominal distension and lower limb oedema, Sarah was now struggling to turn herself in bed and required the use of slide sheets to assist with this. She was mobilising to the bathroom with assistance of two people and her frame. Sarah required assistance with meal set up when able to tolerate.

Sarah's mood was low at this point and she was beginning to feel loss of control. Paul was struggling with trying to stay strong for Sarah and admitted his anxieties to the nursing team; he was also concerned about having to give bad news to his children over the phone.

On re-scoring the PCOC Tools:

Phase:

Deteriorating (as Sarah has an overall functional decline and has experienced a new but anticipated problem with sub-acute bowel obstruction)

RUG-ADL:

Bed Mobility score 5,

Toileting score 5,

Transfers score 5,

Eating score 2,

Total Score 17/18.

Problem Severity Score:

Pain score 3,

Other Symptoms 2,

Psychological distress 2,

Family distress 2,

Total Score 9/12.

AKPS:

50%

SAS:

Patient-rated where possible.

- Distress from difficulty sleeping 3/10,
- Appetite 1/10,
- Nausea 6/10,
- Bowels 8/10,
- Breathing 8/10,
- Fatigue 6/10,
- Pain 8/10.

After commencing a syringe driver Sarah was much more comfortable, constipation had resolved, abdominal pain was now mild in nature and nausea had subsided. Fatigue was severe. Some medication changes were still being made in order to maximise patient comfort, but these were for existing problems.

Sarah and Paul were experiencing mild distress but found pastoral care and social work a good support. They were planning for Sarah to be cared for at home and their two children had returned from abroad to support their parents at home. Functional status remained the same.

On re-scoring the PCOC Tools:

Phase:

Stable (as there was a plan of care in place and although Sarah was at a lower functional level her needs were being met by the current plan of care in place. Further interventions to maintain symptom management were planned.)

RUG-ADL:

Remains at 17/18

Problem Severity Score:

Pain score 1,

Other symptoms 3,

Psychological distress 1,

Family distress 1,

Total Score 6/12.

AKPS:

50% (Required considerable assistance)

SAS:

Patient-rated where possible.

- Distress from difficulty sleeping 2/10,
- Appetite 2/10,
- Nausea 1/10,
- Bowels 1/10,
- Breathing 8/10,
- Fatigue 6/10,
- Pain 3/10.

Sarah's symptoms remained stable. She was discharged from the unit to the care of the community palliative care team. Sarah remained at home until she died three weeks later.

CASE 3:

Situation: Mary was a 68-year-old woman admitted to the palliative care unit complaining of confusion, upper thoracic spine pain, jerking and temperatures.

Background: Mary had a diagnosis of metastatic breast cancer with widespread bone metastases, including spinal metastases. She had been treated with chemotherapy and radiotherapy and was not a candidate for further treatment. Her back pain had been well controlled with OxyContin 80mg b.d. at home.

Assessment: Mary was very confused and disorientated. Her family said that she had been very clear and bright up to two days ago, when she became suddenly confused. She was clearly in distress from her back pain, and she said that this pain was not as bad as it had been before but was still significant. She was mildly nauseated and severely constipated and very agitated and distressed. Her family were understandably concerned by her distress but were managing their distress well. On examination she was myoclonic. Her blood assessment showed a raised urea and creatinine and a corrected calcium of 3.02 mmol/l. Mary had urinary frequency, burning when passing urine and was diagnosed with a UTI. She had no shortness of breath. Functionally, she was able to mobilise but only with assistance of 1 person without any aid, to the bathroom. She was usually confined to her bed and very tired and was able to move around the bed with one person's help. Mary had become unable to feed herself in the past few days but could when assisted. Mary had a poor appetite and was unable to sleep.

PCOC Tools:

Phase:

Unstable

RUG-ADL:

Bed mobility: 3,

Toileting: 3,

Transfers: 3,

Eating: 2,

Total: 11/18.

Problem Severity Score:

Pain: 2,

Other symptoms: 3,

Psychological distress: 3,

Family distress: 1,

Total Score: 9/12.

AKPS:

40%

SAS:

Proxy-rated due to delirium.

- Distress from difficulty sleeping 8/10,
- Appetite 2/10 (poor appetite, but this was not distressing her),
- Nausea 7/10,
- Bowels 8/10,
- Breathing 0/10,
- Fatigue 6/10,
- Pain: 6/10.

Mary was treated with bisphosphonates and IV fluids, IV antibiotics, laxatives, opioid rotation and titration of hydromorphone. In the following 48 hours Mary became lucid, her agitation and myoclonus disappeared, as did her nausea. Her pain improved greatly and was now described as mild. She had several large bowel motions. She was able now to feed herself but still needed assistance of one person to go to the bathroom. She was no longer distressed and her family were very happy with her overall improvement.

On re-scoring the PCOC Tools:

Phase:

Stable

RUG-ADL:

Bed mobility: 3,

Toileting: 3,

Transfers: 3,

Eating: 1,

Total: 10/18.

Problem Severity Score:

Pain: 1,

Other symptoms: 0,

Psychological distress: 0,

Family distress: 0,

Total Score: 1/12.

AKPS:

50% (sitting out for periods during the day)

SAS:

Patient-rated.

- Distress from difficulty sleeping 0/10,
- Appetite 0/10 (poor appetite, but this was not distressing her),
- Nausea 0/10,
- Bowels 0/10,
- Breathing 0/10,
- Fatigue 3/10,
- Pain: 2/10.

Over the coming week, Mary engaged with physiotherapy, and other elements of the MDT. Her mobility improved to the level where she only needed supervision but could mobilise without assistance. Her symptoms remained well controlled.

On re-scoring the PCOC Tools:

Phase:

Stable

RUG-ADL:

Bed mobility: 1,

Toileting: 1,

Transfers: 1,

Eating: 1,

Total: 4/18.

Problem Severity Score:

Pain: 1,

Other symptoms: 0,

Psychological distress: 0,

Family distress: 0,

Total Score: 1/12.

AKPS:

70%

SAS:

Patient-rated.

- Distress from difficulty sleeping 0/10,
- Appetite 0/10 (poor appetite, but this was not distressing her),
- Nausea 0/10,
- Bowels 0/10,
- Breathing 0/10,
- Fatigue 2/10,
- Pain: 2/10.

Mary was discharged home with the support of the community palliative care team.

CASE 4:

Situation: David was a 69-year-old man admitted to the IPU with chest wall pain, nausea, constipation, breathlessness and a lower respiratory tract infection.

Background: Non-small cell lung cancer with mediastinal lymphadenopathy and bony metastases to the thoracic spine and newly diagnosed brain metastases treated with Whole brain radiotherapy.

Assessment: David was clearly wincing with severe pain on inspiration in his right chest wall anteriorly. He had reduced air entry in this area with audible crackles on auscultation. He described he breathlessness as moderate. He was not confused and had no headache. He said he was very nauseated and had been vomiting at home when he was trying to take the antibiotics that his GP had prescribed for him. He had been very constipated for 7 days as he had not been co prescribed a laxative when commenced on oral opioids. In the past 2 days his mobility had greatly reduced due to pain and general decline. Now he was only able to mobilise to the bathroom with the assistance of one. He was able to move around the bed on his own and feed himself unaided though he had a poor appetite. Because of all of this, he said he was upset but had been worse. His family were concerned appropriately, but not excessively distressed.

PCOC Tools:

Phase:

Unstable

RUG-ADL:

Bed mobility: 1

Toileting: 3,

Transfers: 3,

Eating: 1,

Total: 8/18.

Problem Severity Score:

Pain: 3,

Other symptoms: 3,

Psychological distress: 2,

Family distress: 2,

Total Score: 10/12.

AKPS:

50%

SAS:

Patient-rated.

- Distress from difficulty sleeping 0/10,
- Appetite 4/10,
- Nausea 8/10,
- Bowels 9/10,
- Breathing 8/10,
- Fatigue 4/10,
- Pain: 8/10.

David had a chest X-ray that showed a right-sided consolidation. He also had a CTPA which ruled out a pulmonary embolus. He received IV antibiotics, fluids, laxatives, and was commenced on a syringe driver of metoclopramide and morphine 20mg (he had been taking MST 10mg bd). Over the next 48 hours his symptoms all improved, however he began to globally deteriorate from a functional perspective. He was now confined to bed and needed 2 people to help him move in bed. His pain resolved, as did his shortness of breath. His nausea and vomiting improved but he began to become more lethargic and weaker/ more fatigued. His blood analysis shows no acute metabolic issue that could be reversed. Although he was weakening, he said he was comfortable and not distressed. His family said that they had been expecting this decline for some time and were happy that he was more comfortable.

On re-scoring the PCOC Tools:

Phase:

Deteriorating

RUG-ADL:

Bed mobility: 5,

Toileting: 5,

Transfers: 5,

Eating: 3,

Total: 18/18.

Problem Severity Score:

Pain: 0,

Other symptoms: 1,

Psychological distress: 0,

Family distress: 0,

Total Score: 1/12.

AKPS:

20% (sitting out for periods during the day)

SAS:

Patient-rated.

- Distress from difficulty sleeping 0/10,
- Appetite 0/10 (poor appetite, but this was not distressing him),
- Nausea 0/10,
- Bowels 0/10,
- Breathing 0/10,
- Fatigue 6/10,
- Pain: 0/10.

Over the next 48 hours David entered the terminal phase and died comfortably with his family around him.

CASE 5:

Situation: Helen was a 43-year-old separated lady admitted to the IPU for symptom management of severe pain in her upper and mid-thoracic spine. She also had ongoing pain in her suprapubic region and pelvis.

Background: Helen was diagnosed with metastatic cervical cancer four years previously and had chemotherapy and radiotherapy. Two years later she developed disease progression involving regional lymph nodes and her thoracic spine. At that stage Helen was informed that she was not suitable for further chemotherapy, but she received radiotherapy for her spinal metastases. Her symptoms had been well controlled since then with the involvement of the SPC Community Team.

Assessment: On admission, Helen was complaining of severe back pain in her thoracic region radiating down her right arm. She was tender to palpation of the upper and mid-thoracic spine and she described the pain down her arm as shooting and stinging. Helen described the pain in her back as a dull throbbing pain. She suffered from moderate fatigue and occasional dyspnoea on mild exertion and poor appetite. She was moderately distressed at the prospect of leaving her 3 children when she died. Her family were mildly distressed at her need for admission to a hospice but also relieved that her pain was going to be addressed. Functionally she needed someone to assist her in going to the bathroom and need a small amount of assistance in washing and dressing. She was able to move in her bed independently and was able to eat independently.

PCOC Tools:

Phase:

Unstable (sudden onset of pain with no care plan in place)

RUG-ADL:

Bed mobility: 1,

Toileting: 3,

Transfers: 3,

Eating: 1,

Total: 8/18.

Problem Severity Score:

Pain: 3,

Other symptoms: 2,

Psychological distress: 2,

Family distress: 1,

Total Score: 8/12.

AKPS:

60%

SAS:

Patient-rated.

- Distress from difficulty sleeping 5/10,
- Appetite 7/10,
- Nausea 0/10,
- Bowels 0/10,
- Breathing 3/10,
- Fatigue 6/10,
- Pain: 9/10.

To manage her symptoms Helen's dose of oral opioid was increased, she was started on an oral steroid and pregabalin. She was referred for an MRI spine which was completed the following day. There was no evidence of a spinal cord compression however on discussion with radiation oncology there was no scope for further radiotherapy as she had reached the maximal dose for that area of her spine. The introduction of a steroid and pregabalin as well as the titration of her opioid greatly improved her painful back and arm symptoms. Her energy improved as did her appetite and her functional status. She became independent and was able to go to the bathroom unassisted, however did need a raised toilet seat to be able to manage. Psychologically she was much improved and happy to be in the IPU having her pain controlled as were her family. Her aim was to rehabilitate as much as possible and go back home.

On re-scoring the PCOC Tools:

Phase:

Stable

RUG-ADL:

Bed mobility: 1,

Toileting: 1,

Transfers: 1,

Eating: 1,

Total: 4/18.

Problem Severity Score:

Pain: 1,

Other symptoms: 1,

Psychological distress: 0,

Family distress: 0,

Total Score: 2/12.

AKPS:

70%

SAS:

Patient-rated.

- Distress from difficulty sleeping 0/10,
- Appetite 0/10, (poor appetite, but this was not distressing her).
- Nausea 0/10,
- Bowels 0/10,
- Breathing 2/10,
- Fatigue 2/10,
- Pain: 2/10.

Three days later, Helen experienced severe pleuritic chest pain and shortness of breath and a non-productive cough. Her functional status declined again, and she returned to needing the assistance of one person to toilet and transfer. She was now short of breath on talking. Her fatigue became severe once again. She had a CTPA the following day after having anticoagulation therapy. The CTPA showed no evidence of a pulmonary embolus, however there was evidence of new lung metastases that were invading the pleura.

On re-scoring the PCOC Tools:

Phase:

Unstable (Acute unanticipated uncontrolled symptoms without a care plan in place for this new symptom)

RUG-ADL:

Bed mobility: 3,

Toileting: 4 (assistance of 1 person and an aid, the toilet seat raised),

Transfers: 3,

Eating: 1,

Total: 11/18.

Problem Severity Score:

Pain: 3,

Other symptoms: 3,

Psychological distress: 2,

Family distress: 2,

Total Score: 10/12.

AKPS:

40%

SAS:

Patient-rated.

- Distress from difficulty sleeping 0/10,
- Appetite 0/10, (poor appetite, but this was not distressing her at this point),
- Nausea 0/10,
- Bowels 0/10,
- Breathing 8/10,
- Fatigue 8/10,
- Pain: 9/10.

After adjusting her symptom control medications Helen's pain improved as did her dyspnoea. However, her overall functional ability progressively declined over the next week and her serum albumin dropped significantly to 19. Helen was now confined to bed requiring the assistance of two people for all ADLs. She needed help to set up for eating however when food arrived, she had no appetite.

On re-scoring the PCOC Tools:

Phase:

Deteriorating

RUG-ADL:

Bed mobility: 5,

Toileting: 5,

Transfers: 5,

Eating: 2,

Total: 17/18.

Problem Severity Score:

Pain: 1,

Other symptoms: 1,

Psychological distress: 2,

Family distress: 2,

Problem Severity Score Total: 6/12.

AKPS:

20%

SAS:

Patient-rated.

- Distress from difficulty sleeping 0/10,
- Appetite 0/10 (poor appetite, but this was not distressing her at this point),
- Nausea 0/10,
- Bowels 0/10,
- Breathing 2/10,
- Fatigue 8/10,
- Pain: 2/10.

Helen then entered the terminal phase of her illness 2 days later but was very comfortable towards the end of her life showing no signs of distress. She died peacefully.

CASE 6:

Situation: Jack was admitted to the IPU for management of severe pelvic pain, which had been minimally responsive to standard analgesia in the community.

Background: Jack was a 54-year-old man with a diagnosis of pelvic osteosarcoma with lung and brain metastases. He suffered from seizures and often bit his tongue during these causing lacerations.

He was treated with chemotherapy however this was unsuccessful. Jack's cancer progressed, and he developed lung and brain metastases. His brain metastases caused recurrent seizures that were controlled with anti-epileptic medications.

Assessment: On examination he was clearly distressed and scored his pain as 10/10 and dull in nature but with shooting exacerbations into his left leg. He was septic on admission with a temperature of 38.7 degrees Celsius. Laboratory analysis confirmed a UTI. He had had no bowel action for the past week and had significant nausea. He was able to mobilise with the assistance of 1 person and a frame. He required a raised toilet seat. He was independent moving in the bed and with eating. Psychologically, he was distressed and delirious due to both sepsis and hypercalcaemia. His family were very distressed especially at his recent acute decline.

PCOC Tools:

Phase:

Unstable

RUG-ADL:

Bed mobility: 1,

Toileting: 4 (assistance of 1 person and an aid, a raised toilet seat),

Transfers: 4,

Eating: 1,

Total: 10/18.

Problem Severity Score:

Pain: 3,

Other symptoms: 3,

Psychological distress: 3,

Family distress: 3,

Total Score: 12/12.

AKPS:

40%

SAS:

Patient-rated.

- Distress from difficulty sleeping 0/10,
- Appetite 6/10,
- Nausea 8/10,
- Bowels 8/10,
- Breathing 0/10,
- Fatigue 1/10,
- Pain: 10/10.

Jack was admitted and treated with IV antibiotics and IV fluids followed by zoledronic acid. Due to opioid toxicity he was commenced on a syringe driver of alfentanil for pain and metoclopramide for nausea He was commenced on steroid therapy and pregabalin while his laxatives were titrated with good effect. Overall, his pain was significantly better but not gone. Despite all of this, his functional ability remained unchanged but both he and his family stated that they were very relieved and not anxious or distressed.

On re-scoring the PCOC Tools:

Phase:

Stable

RUG-ADL:

Bed mobility: 1,

Toileting: 4 (assistance of 1 person and an aid, the toilet seat raised),

Transfers: 4,

Eating: 1,

Total: 10/18.

Problem Severity Score:

Pain: 1,

Other symptoms: 1,

Psychological distress: 1,

Family distress: 2,

Total Score: 5/12.

AKPS:

40%

SAS:

Patient-rated.

- Distress from difficulty sleeping 0/10,
- Appetite 0/10,
- Nausea 0/10,
- Bowels 0/10,
- Breathing 0/10,
- Fatigue 1/10,
- Pain: 2/10.

The plan was that Jack would be discharged to home with support from the SPC Community Team, but on the day of discharge he developed a cold and painful left leg. On examination he had absent pulsations and his leg appeared mottled and was cold to touch. An urgent vascular opinion was sought and Jack was admitted to hospital where an arteriogram performed showed complete occlusion of his left femoral artery. The vascular team felt that no surgical or radiological intervention was possible. He was transferred back to the IPU. His pain was again significant, rated as 6/10 and he was both very upset and profoundly weak at this stage. On discussion with Jack and his family it was made clear that he wanted the focus of care to be on symptom control and that he wanted neither further investigations nor IV treatments.

On re-scoring the PCOC Tools:

Phase:

Unstable

RUG-ADL:

Bed mobility: 5,

Toileting: 5,

Transfers: 5,

Eating: 2,

Total: 17/18.

Problem Severity Score:

Pain: 2,

Other symptoms: 3,

Psychological distress: 3,

Family distress: 2,

Total Score: 10/12.

AKPS:

20%

SAS:

Patient-rated.

- Distress from difficulty sleeping 0/10,
- Appetite 0/10 (poor appetite, but this was not distressing her at this point),
- Nausea 0/10,
- Bowels 0/10,
- Breathing 0/10,
- Fatigue 10/10,
- Pain: 6/10.

Over the coming days, John entered the terminal phase of his illness. His symptoms were well controlled, and he died peacefully with his family in attendance. His PCOC scores on the day before he died were as follows:

On re-scoring the PCOC Tools:

Phase:

Terminal

RUG-ADL:

Bed mobility: 5,

Toileting: 5 (assistance of 1 person and an aid, the toilet seat raised),

Transfers: 5,

Eating: 3,

Total: 18/18.

Problem Severity Score:

Pain: 0,

Other symptoms: 0,

Psychological distress: 0,

Family distress: 1,

Total Score: 1/12.

AKPS:

10%

SAS:

Proxy scoring with a family member.

- Distress from difficulty sleeping 0/10.
- Appetite 0/10, (poor appetite, but this was not distressing her at this point).
- Nausea 0/10,
- Bowels 0/10,
- Breathing 0/10,
- Fatigue 0/10,
- Pain: 0/10.

CASE 7:

Situation: Catherine was a 57-year-old lady admitted to the SPU suffering from severe shortness of breath and productive cough.

Background: Catherine had a diagnosis of advanced idiopathic pulmonary fibrosis. She had needed recurrent hospital admissions for lower respiratory tract infections. Her functional status had declined in recent months and now she needed assistance of 1 to mobilise to the bathroom. She did not need a frame and was able to use the toilet with the assistance of one person. She was able to move around the bed herself without help and able to eat unassisted. Psychologically, she had been expecting this deterioration and had prepared herself for it. She had made her will and funeral arrangements with her family and they were all aware of her short prognosis. Due to her poor functional status and shortness of breath she remained in bed most of the day.

PCOC Tools:

Phase:

Unstable

RUG-ADL:

Bed mobility: 1,

Toileting: 3,

Transfers: 3,

Eating: 1,

Total: 8/18.

Problem Severity Score:

Pain: 0,

Other symptoms: 3,

Psychological distress: 1,

Family distress: 1,

Total Score: 5/12.

AKPS:

40%

SAS:

Patient-rated.

- Distress from difficulty sleeping 0/10.
- Appetite 0/10, (poor appetite, but this was not distressing her at this point).
- Nausea 0/10,
- Bowels 0/10,
- Breathing 9/10,
- Fatigue 8/10,
- Pain: 0/10.

After discussion with Catherine, she decided that she didn't want to have either IV or oral antibiotics and her family agreed with this. They had discussed this previously at home and were aware that this time would come. Catherine wanted to be comfortable at the end of her life. She was commenced on a low dose syringe driver of morphine sulphate and buscopan for dyspnoea and respiratory secretions. She settled well over the coming 48 hours and was comfortable however she progressively weakened and became bedbound and minimally rousable. Prognosis was expected to be a day or two.

On re-scoring the PCOC Tools:

Phase:

Terminal

RUG-ADL:

Bed mobility: 5,

Toileting: 5,

Transfers: 5,

Eating: 3,

Total: 18/18.

Problem Severity Score:

Pain: 0,

Other symptoms: 1,

Psychological distress: 0,

Family distress: 1,

Total Score: 2/12.

AKPS:

10%

SAS:

Proxy scoring with a family member.

- Distress from difficulty sleeping 0/10,
- Appetite 0/10,
- Nausea 0/10,
- Bowels 0/10,
- Breathing 2/10,
- Fatigue 0/10,
- Pain: 2/10.

Catherine died peacefully in the presence of her family.

CASE 8:

Situation: Gary was a 68-year-old man admitted to the IPU as his family were in crisis and unable to meet his care needs at home.

Background: Gary had a diagnosis of Multiple Sclerosis made 5 years ago. He was now bed-bound and required full nursing care. He had no acute medical issues and no acute symptomatology or acute change in his functional status. His family were simply unable to provide his care at home anymore. Both Gary and family were very relieved that he was admitted to the hospice.

PCOC Tools:

Phase:

Stable

RUG-ADL:

Bed mobility: 5,

Toileting: 5,

Transfers: 5,

Eating: 3,

Total: 18/18.

Problem Severity Score:

Pain: 0,

Other symptoms: 0,

Psychological distress: 1,

Family distress: 1,

Total Score: 2/12.

AKPS:

30%

SAS:

Patient-rated.

- Distress from difficulty sleeping 0/10,
- Appetite 0/10,
- Nausea 0/10,
- Bowels 4/10,
- Breathing 0/10,
- Fatigue 4/10,
- Pain: 0/10.

Social work became involved and planning for long term care was initiated. After a week Gary's daughter arrived back from the United States. She had been estranged from her mother and siblings but had always kept in contact with her father Gary.

His daughter worked in medical administration in the United States and was very angry when she arrived on the ward. She said that none of her family had contacted her about Gary's admission and that she had only found out by chance. She said that he was on too much medication and that this was the reason that he was unable to mobilise. There was a big row in Gary's room and hospice staff had to intervene due to shouting on the ward. Gary's medical condition remained unchanged at this stage.

On re-scoring the PCOC Tools:

Phase:

Unstable. This is because although Gary's condition remains unchanged there has be a sudden unanticipated change in his family's distress that has not been planned for and as of yet there is no plan in place. This is causing Gary understandable psychological distress.

RUG-ADL:

Bed mobility: 5,

Toileting: 5,

Transfers: 5,

Eating: 3,

Total: 18/18.

Problem Severity Score:

Pain: 0,

Other symptoms: 1,

Psychological distress: 3,

Family distress: 3,

Total Score: 7/12.

AKPS:

30%

SAS:

Patient-rated.

- Distress from difficulty sleeping 0/10,
- Appetite 0/10,
- Nausea 0/10,
- Bowels 0/10,
- Breathing 0/10,
- Fatigue 2/10,
- Pain: 2/10.

With Gary's consent social work and pastoral care staff addressed the situation with his family and the medical team met with Gary's daughter and explained his medical management. A full family MDT was arranged thereafter and the tension in the family eased substantially.

On re-scoring the PCOC Tools:

Phase:

Stable (As both Gary's and his family's psychological distress had eased significantly).

RUG-ADL:

Bed mobility: 5,

Toileting: 5,

Transfers: 5,

Eating: 3,

Total: 18/18.

Problem Severity Score:

Pain: 0,

Other symptoms: 1,

Psychological distress: 0,

Family distress: 1,

Total Score: 2/12.

AKPS:

30%

SAS:

Patient-rated.

- Distress from difficulty sleeping 0/10,
- Appetite 0/10,
- Nausea 0/10,
- Bowels 0/10,
- Breathing 0/10,
- Fatigue 2/10,
- Pain: 2/10.

Thereafter, Gary was transferred to a long-term care facility close to his home.

CASE 9:

Situation: Lester was admitted to the IPU with worsening headache, nausea and vomiting, somnolence and diplopia.

Background: Lester was a 48-year-old man who had a CNS lymphoma with a significant cerebral burden of disease. He was unable to tolerate chemotherapy and radiotherapy had been completed 3 months previously. He was not for any further oncological treatment.

Assessment: On admission, Lester was very drowsy and grimacing with pain. He was unable to score his pain however he was visibly distressed. His family had cared for him at home but were now unable to meet his needs. He had become confined to bed, required full nursing care, but was still able to feed himself and drink. In recent weeks his legs had become very oedematous and as consequence the use of a hoist was required for transfers. Of note his steroids had been discontinued the previous week due to this. He said during the assessment 'please someone help me I've never felt so bad'. His family were very upset at his distress.

PCOC Tools:

Phase:

Unstable

RUG-ADL:

Bed mobility: 5,

Toileting: 5,

Transfers: 5,

Eating: 1,

Total: 16/18.

Problem Severity Score:

Pain: 3,

Other symptoms: 3,

Psychological distress: 3,

Family distress: 3,

Total Score: 12/12.

AKPS:

40%

SAS:

Proxy scored with a family member.

- Distress from difficulty sleeping 0/10,
- Appetite 0/10,
- Nausea 10/10,
- Bowels 0/10,
- Breathing 0/10,
- Fatigue 10/10,
- Pain: 10/10.

Lester was commenced on dexamethasone 8mg once daily and a syringe driver to manage pain, nausea, vomiting and agitation. That night he required additional stat doses of medications for pain and agitation.

Over the next 24 hours Lester's headaches improved dramatically as did his, nausea, vomiting and agitation. He was greatly relieved that he was no longer in pain. His family were also very relieved to see his improvement.

On re-scoring the PCOC Tools:

Phase:

Stable

RUG-ADL:

Bed mobility: 5,

Toileting: 5,

Transfers: 5,

Eating: 1,

Total: 16/18.

Problem Severity Score:

Pain: 0,

Other symptoms: 1,

Psychological distress: 1,

Family distress: 1,

Total Score: 3/12.

AKPS:

40%

SAS:

Patient-rated.

- Distress from difficulty sleeping 0/10,
- Appetite 0/10,
- Nausea 0/10,
- Bowels 0/10,
- Breathing 0/10,
- Fatigue 4/10,
- Pain: 1/10.

Lester received full MDT input over the next two weeks including physiotherapy for transfers and oedematous legs, and occupational therapy for equipment. His symptoms remained controlled and he became able to be transferred with one person and a frame. He decided with his family, that he wanted to go home again. They were in favour of this also and were all very happy with this plan.

On the day prior to discharge, Lester began to complain once again of headaches and had grand mal seizures. He then became unresponsive. On assessment his pupils were dilated and unresponsive to light. He was unresponsive to all verbal and tactile stimuli and his breathing became deep and laboured. The medical team made a provisional diagnosis of an intracranial haemorrhagic event most likely caused by a bleed into his cerebral lymphoma. He was unfit for transfer for a CT scan and in any case, he was not a candidate for surgical intervention. His family although surprised by this change, had been expecting something like this and wanted him kept comfortable. His seizures stopped spontaneously, and he was recommenced on a syringe driver for ongoing symptom management.

On re-scoring the PCOC Tools:

Phase:

Terminal

RUG-ADL:

Bed mobility: 5,

Toileting: 5,

Transfers: 5,

Eating: 3,

Total: 18/18.

Problem Severity Score:

Pain: 0,

Other symptoms: 0,

Psychological distress: 0,

Family distress: 1,

Total Score: 1/12.

AKPS:

10%

SAS:

Proxy scored.

- Distress from difficulty sleeping 0/10,
- Appetite 0/10,
- Nausea 0/10,
- Bowels 0/10,
- Breathing 0/10,
- Fatigue 0/10,
- Pain: 0/10.

Lester continued to weaken and died twelve hours later.

CASE 10:

Situation: Jenny was a 92-year-old lady transferred from hospital to the IPU for end of life care. She had been admitted to hospital with the latest in a series of recurrent aspiration pneumonias but her condition had deteriorated despite appropriate medical intervention.

Background: Jenny had advanced dementia and a nursing home resident for the past 9 (nine) years. She had been widowed for the past 19 years. She also had multiple medical comorbidities including chronic renal failure, hypothyroidism and diabetes (type 2). She had three adult children, all very caring for her and 9 grandchildren. She had multiple admissions in the past 4 years for aspiration pneumonia and urinary tract infections. She was confined to bed, unable to move in the bed or transfer. She was on a pureed diet and thickened fluids yet still was aspirating. She was non-verbal and unable to communicate.

Assessment: On admission Jenny was very symptomatic of marked oropharyngeal secretions and was objectively straining with breathing. She was agitated and reaching out in the bed while moaning and looked like she was in pain and distress.

She was confined to bed and unable to eat or drink. Her family were relieved that she was in the hospice and that she was not going back to hospital for IV treatment. They had seen her suffer from recurrent hospital admissions in recent times and did not want her to have further treatment that, as they described it, 'is prolonging her suffering.'

PCOC Scores:

Phase:

Unstable

RUG-ADL:

Bed mobility: 5,

Toileting: 5,

Transfers: 5,

Eating: 3,

Total: 18/18.

Problem Severity Score:

Pain: 3,

Other symptoms: 3,

Psychological distress: 2,

Family distress: 1,

Total Score: 9/12.

AKPS:

20%

SAS:

Proxy scored with a family member.

- Distress from difficulty sleeping 0/10,
- Appetite 0/10,
- Nausea 10/10,
- Bowels 0/10,
- Breathing 10/10,
- Fatigue 0/10,
- Pain: 5/10.

Jenny was commenced on a syringe driver containing analgesia to manage both pain and shortness of breath, the antipsychotic haloperidol to manage delirium and as antiemetic cover and low dose benzodiazepine (midazolam) as an adjunct for agitation and distress.

Jenny settled over the next few hours with the assistance of some stat medicines but continued to progressively weaken with her family in attendance. They were relieved that she was comfortable and that she did not appear distressed as she approached her end of life.

On re-scoring the PCOC Tools:

PCOC Scores:

Phase:

Terminal

RUG-ADL:

Bed mobility: 5,

Toileting: 5,

Transfers: 5,

Eating: 3,

Total: 18/18.

Problem Severity Score:

Pain: 0,

Other symptoms: 0,

Psychological distress: 0,

Family distress: 1,

Problem Severity Score Total: 1/12.

AKPS:

10%

SAS:

Proxy scored with a family member.

- Distress from difficulty sleeping 0/10,
- Appetite 0/10,
- Nausea 0/10,
- Bowels 0/10,
- Breathing 0/10,
- Fatigue 0/10,
- Pain: 0/10,

Jenny died peacefully with her family in attendance the following morning.

PCOC
Self-test Questions

Question 1:

Peter is a 60-year-old man who has metastatic bowel cancer with liver and lung metastases.

He is referred to you after finishing palliative chemotherapy for symptom management and ongoing support.

He is married with two daughters aged 22 and 18. He lives with his wife and 18-year-old daughter.

On initial review Peter has:

- Ongoing right lower abdominal pain treated with oxycontin 30mg bd and oxynorm as needed. He is still experiencing pain and needs oxynorm for this three times a day. His oxycontin was last increased 1 week ago at an OPD.
- He has shortness of breath on minimal exertion but not at rest.
- He has a good appetite, sleeps well.
- He is worried about his prognosis and sad at his recent news that his cancer is progressing and there is no further treatment but does not say that he is distressed or anxious.
- He mobilises with no assistance, though this is limited by his shortness of breath.
- He can wash and use the bathroom unassisted.
- His wife is very upset as is his daughter and they attend the cancer counselling service.

Which of these statements is correct? *(please tick)*

1. Peter is in the unstable phase as he has pain, shortness of breath and his wife and daughter are very upset. ☐
2. Peter's care problem severity scores add up to 9 out of 12. ☐

3. Peter's SAS scores could add up to 16. ☐

4. Peter's RUG-ADL score reflects what he feels he can do around the house. ☐

5. Peter should have a titration of his long acting opioid and be referred for physiotherapy assessment and breathlessness management as part of his MDT review. ☐

Question 2:

Elizabeth is a 72-year-old woman with a diagnosis of ovarian carcinoma with peritoneal metastases. She has been treated with chemotherapy and has been informed that she is not suitable for further treatment by her oncologist. Elizabeth is married and has 3 sons and one daughter.

Elizabeth is referred to the specialist palliative care community services and on her initial visit she reports new onset vomiting. She is surprised as she didn't feel any nausea and it was spontaneous and large in volume. She is referred into the IPU for further management.

On initial review in the unit, Elizabeth:

- Has a distended abdomen, which has now become painful. She says it isn't bad and she would classify this as mild pain 'more like a tightness'.
- She reports feeling mildly short of breath today, as her abdomen is so distended.
- She reports that although she was mobilising well earlier in the week, she now notes that her ability to walk is greatly reduced in the last two days.
- She is still able to wash herself but now needs the help of one person due to her weakened condition. She can eat independently however due to her distended abdomen she needs assistance to move around her bed.
- Elizabeth can mobilise to the bathroom but needs the assistance of one person as she feels weak.
- She is still vomiting repeatedly, with no warning but only a small amount of fluid is coming out. She rates this retching as severe.

- She is not passing faeces but has passed some flatus today.
- She is not surprised her condition is worsening and has prepared herself for this. She denies feeling anxious or worried but just would like her symptoms addressed, but her family are distraught, as they were not expecting such an acute deterioration when she had been so well earlier in the week.

Which of these statements is correct? (please tick)

1. Elizabeth is in the deteriorating phase of her illness because her mobility is reduced, and her symptoms have progressed.
2. Elizabeth's problem severity score is 7/12.
3. Elizabeth's RUG-ADL is 17/18.
4. Elizabeth's AKPS is 40%.

Question 3:

Are these statements relating to PCOC true or false?

1. The problem severity score is a patient-rated tool but can be assisted by a clinician. ☐
2. The RUG-ADL is a measure of what a patient does functionally and not what they say they can do. ☐
3. The SAS is designed to be a patient-rated tool but also allows for rating by proxy. ☐
4. A patient can go from a terminal phase to a deteriorating phase. ☐
5. If documented correctly the PCPSS scores should correlate with the SAS scores. ☐
6. The AKPS measures observations of a patient's ability to perform common tasks relating to activity, work and self-care. ☐

Question 4:

Alex is a 47-year-old man with motor neurone disease for the past 3 years. Recently he has significantly deteriorated from both a symptom perspective and a functional perspective. On admission to the unit:

- Alex describes a 3-day history of significantly worsening shortness of breath and difficulty coughing up phlegm. He describes his dyspnoea as 'severe'.
- He denies any pain.
- He also has developed a temperature (38.7 degrees Centigrade).
- In the past month, Alex is mostly bed bound and cannot mobilise to the bathroom and needs the assistance of one person (his wife) while using a bed lever to move in the bed. He does however have a urinary catheter in place for the last week.
- Alex finds it difficult to eat as he has a greatly reduced appetite in the past few weeks. As he was a food blogger in the past and loved to eat, he finds this very distressing. He is still able to eat unassisted when he wants to.
- Psychologically, Alex is very upset and distressed at his recent deterioration as are his wife and two young children.

Which of these statements is true? (please tick)

1. On admission, Alex's problem severity score is 9/12. ☐
2. His RUG-ADL is 15/18. ☐
3. When Alex completes the SAS, he rates his dyspnoea as a 3 out of 10 and his appetite problems as 2 out of 10. It is clear that Alex fully understands the SAS rating scale. ☐
4. Alex's phase on admission is recorded as deteriorating. ☐
5. Alex's AKPS is 20%. ☐

Question 5:

Brendan is a 73-year old farmer with pulmonary fibrosis who has been admitted to the IPU two days ago. You were looking after him yesterday and recorded the following PCOC scores for him:

Phase	RUG-ADL	PSS	AKPS	SAS (Patient-rated)	
Stable	4/18	2/12	70%	Sleeping	4
				Appetite	0
				Nausea	0
				Bowels	2
				Breathing	3
				Fatigue	3
				Pain	0

After finishing his breakfast this morning his breathlessness has suddenly worsened, and he is very frightened. You confirm that his oxygen saturations have dropped from his normal 86% to 74% on two litres of oxygen. His systolic blood pressure has dropped to 90mmHg and his heart rate is 140/min. He complains of severe stabbing chest pain when he takes a deep breath. You have given him a short-acting benzodiazepine to help him relax until he is seen by the medical team, but he remains too petrified to close his eyes. He asks to get to the bathroom but is clearly too weak to get out of bed at the minute and requires the assistance of two people for all ADLs.

Brendan's partner Joseph and their two adopted 21-year old daughters have arrived. They are very distressed to see him looking so frightened and one of them runs out of the room.

Question:

Complete today's PCOC scores for Brendan, based on the clinical information above:

Phase	RUG-ADL	PSS	AKPS	SAS (Patient-rated)
				Sleeping 6
				Appetite 0
				Nausea 2
				Bowels 2
				Breathing 9
				Fatigue 1
				Pain 8

Question 6:

Aisling is a thirty-seven-year-old single lady with metastatic malignant melanoma. Her original disease was surgically removed from her left arm five years ago following which she developed recurrent disease controlled by targeted therapy for some years. More recently she completed whole brain radiation therapy, which in addition to her disease has led to her becoming very fatigued, nauseated, unsteady on her feet and nervous of being at home alone. She was seen by a Consultant in Palliative Medicine at the local hospital and a plan was put in place to commence oral corticosteroids for symptom benefit and to admit her to the IPU for her symptoms to be further managed and for rehabilitation.

Question 6a: *What is Aisling's current phase of illness?*

Two days after admission to the IPU, the nurse looking after Aisling mentions that she complained to her early that morning of a dull right-sided headache and worsening low-grade nausea. Her parents have become distressed by Aisling's feeling less well and are themselves needing more support from the care team.

Question 6b: *What is Aisling's current phase of illness?*

The clinical team review Aisling's plan of care and both slightly increase her dose of corticosteroid and commence cyclizine thrice daily. Her headaches and nausea are fully controlled, and she begins to enjoy an appetite again. Her parents are delighted. The team begin to discuss planning her discharge to her home with SPC Community Service follow-up.

Question 6c: *What is Aisling's current phase of illness?*

Question 7:

Are these statements relating to PCOC true or false?

1. When completing a RUG-ADL for eating, a patient who requires assistance from nursing staff to be fed via a PEG feeding tube will score 2. ☐
2. An AKPS of 50% is consistent with a patient who requires occasional assistance but can care for most of his or her needs. ☐
3. A patient who has mild pain, mild dyspnoea, mild nausea, severe constipation, moderate psychological distress and whose partner is severely distressed will have a total PCPSS of 9/12. ☐
4. When a patient scores each of the seven SAS symptoms as a 2, it means that he or she is severely distressed by each symptom with a total SAS score of 14. ☐
5. A patient who enters the unstable phase due to a sudden increase in their pain is reviewed and an urgent change is made to the plan of care. Four hours later the nurse in charge observes the patient to be more comfortable. The nurse is correct in deciding that the patient is now in the stable phase again. ☐

Question 8:

Frank is a 74-year-old man who has been referred to your hospital Specialist Palliative Care Team by the local Radiation Oncology service. He has locally advanced inoperable squamous cell carcinoma of the upper oesophagus and is about to complete concurrent chemotherapy and long-course radical radiation therapy.

Frank is experiencing acute severe pain from oropharyngeal mucositis and from unpleasant herpes zoster infection involving the right side of his face and neck. His doctors have prescribed around the clock and as required opioid analgesia, pregabalin and amitryptiline for his pain. He is severely fatigued, moderately nauseated and mildly constipated. Though he has lost three stone in weight he has no appetite and can just tolerate bolus PEG feeding which he administers himself. A fiercely independent man, Frank is moderately distressed that a nurse needs to watch him get out of bed and walk to the bathroom but is relieved that the nurse doesn't need to help him. At the present, Frank is resolutely caring for himself, but hasn't been able to work for some months. His nearest relative is a distant cousin and he isn't remotely distressed by what's going on for Frank.

Question 8a: *Complete Frank's current PCOC Scores*

Phase	RUG-ADL	PSS	AKPS
	/18	/12	%

A week later Frank remains pain free, but he begins to cough each time that he tries to drink anything. He becomes drowsy, intermittently confused, begins to hallucinate and develops myoclonus. He subsequently develops a fever and clinical signs of a right lower lobe pneumonia. He is moderately short of breath. Frank is reviewed by the team and is commenced on IV fluids and antibiotics and is temporarily made nil by mouth. Frank is aware of his confusion and is very distressed by the frightening hallucinations he suffers from. His cousin comes to ask you why Frank is losing his mind and becomes distressed and verbally threatening when you inform him that Frank does not want us to discuss his care with any of his family. Meanwhile. Frank is

now spending over half the time in bed, needs the assistance of one for each of bed mobility, toileting and transfers and is no longer able to competently administer PEG feeding, a task that nursing staff take over for now.

Question 8b: *Complete Frank's current PCOC Scores*

Phase	RUG-ADL	PSS	AKPS
	/18	/12	%

Question 9:

Which of the statements is correct – there may be more than one correct answer in each question (please tick)

1. It is important to record a patient's PCOC scores independently of the scores from the previous day because:
   a. There is often a temptation to just copy the scores from the previous day. ☐
   b. It rarely happens that a patient's condition can change from one day to the next. ☐
   c. If something is worth doing it is worth doing properly. ☐
   d. It is not important to be able to gauge the effectiveness of the care that you and your colleagues provide to your patients on a daily basis. ☐
   e. Your organisation's Quality Assurance team will be regularly auditing PCOC scoring to identify scores that do not reflect the patient's condition. ☐

2. In relation to a change in a patient's phase of illness:
   a. There is no need to re-score all five clinical assessment tools when a phase change occurs. ☐
   b. A patient who enters the unstable phase can only return to the Stable phase once the plan of care has been reviewed again and requires no further changes. ☐
   c. The Terminal phase of illness will always be preceded by the deteriorating phase. ☐
   d. The phase of illness reflects the plan of care that is in place for a patient rather than their physical condition. ☐
   e. A patient can only enter the deteriorating phase if their overall functional status is declining. ☐

3. Organisations that participate in the PCOC programme:

   a. Can anticipate better patient experience and improved outcomes of care across their organisation. ☐

   b. Will receive annual reports of their PCOC data which they can benchmark (compare) against all other participant services. ☐

   c. Receive data reports that are anonymised – only each service will know which data is from their organisation. ☐

   d. Can use their performance against established PCOC benchmarks to strengthen their case for service development including additional staffing and resources. ☐

   e. Are recommended to have in place at least one of the following components:

      i. A PCOC Quality Facilitator. ☐

      ii. A service champion or lead. ☐

      iii. Use of the clinical assessment tools is fully embedded in daily clinical practice. ☐

4. Recording of PCOC data (assessment scores):

   a. Forms a part of the triage, assessment and care planning processes. ☐

   b. Should be recorded at the point of care, which in the inpatient setting, is the patient's bedside. ☐

   c. Should occur at any change of a patient's care plan. ☐

   d. If a patient's PCOC scores for a day cannot be recorded because he or she is on prolonged leave from the IPU, the scores for that day can be left blank. ☐

   e. Should be recorded both on the day of admission and on the day of discharge. ☐

5. In relation to the use of PCOC Assessment Tools in the community setting

   a. Community PCOC incorporates the use of four clinical assessment tools. ☐

   b. May be recorded in person or over the phone by community specialist palliative care staff. ☐

   c. The patient's phase of illness is fully independent of his or her carer's health or ability to sustain the patient's care at home. ☐

   d. PCOC scores are required to be recorded daily. ☐

   e. The carer is often better placed than a clinician to complete the SAS by proxy on the patient's behalf. ☐

Question 10:

Danny is a 72-year-old man with metastatic prostate cancer with bone metastases. He lives alone in poor social circumstances, doesn't take care of himself and there is a concern about his ability to be compliant with his medications. He has no running water and he has an outside toilet. The community specialist palliative care nurse has noticed that he is staggering more when walking around and looks unkempt. He is estranged from his family due to a dispute over his inheritance which has been ongoing for more than 10 years. The request for admission is for respite, rehabilitation and psychosocial support.

When he is admitted to the IPU, he engages well with the MDT who have a plan of care in place for him. When assessed he is able to mobilise, attend to toileting and eat independently. He describes a mild pain in his lower back but says this does not bother him. He does complain of moderate lack of energy, which previously severely distressed him due to its impact on his independence. However, he says he is only a little upset by this now as he has accepted it as part of his illness. He is fully aware of his diagnosis is not bothered about it and says, 'we all eventually get something!' After admission he engages well with the care plan.

Question 10a:

Which of the following statements are correct? (please tick)

1. Danny is in the deteriorating phase when he is admitted. ☐
2. His problem severity score (PSS) on admission is 3. ☐
3. His AKPS is 70%. ☐
4. On his SAS his pain would be expected to be scored at about 8/10 while his fatigue would be expected to score 5/10. ☐
5. His RUG-ADL score is 4/18. ☐

Three days after admission Danny develops worsening back pain late in the evening which he now describes as severe. He describes it as travelling around both sides of his abdomen. The next morning, he has a fall and is unable to urinate. After the fall, he needs the assistance of two people to get back to his bed. That night he needs to be catheterised as he develops

urinary retention. He finds all of this now very upsetting. He is commenced on high dose steroids. The following morning, he has an MRI whole spine which reveals a spinal cord compression at L3/L4. He begins emergency radiotherapy. His estranged family arrive on the ward very angry that they have not been informed that 'he is in a hospice and dying' and they are asking if he has had a lawyer in to him to change his will. Two of the family are very upset at how they have been estranged from Danny over the past few years.

Question 10b:

Which of the following statements is correct? (please tick)

1. Danny's phase is now unstable. ☐
2. Because Danny's PCOC was scored in the evening before he had his fall there is not a need to score is again until the following evening. ☐
3. His new problem severity score is 8/12. ☐
4. His new AKPS is 50%. ☐
5. His new RUG-ADL is 10/18. ☐

Answers to PCOC Self-test Questions

Answers to Question 1:

F/F/F/F/T

1: Although Peter has pain it is not a new symptom and he has recently had a plan put in place at an OPD where this pain was assessed and reviewed. Simple titration of his opioid is part of his plan of care. As such he in in a stable phase. His family are distressed but are already involved in counselling services so again, it is not an acute change and there is a plan in place.

2: This is false. His pain score is 1 out of 3. His other symptoms are mainly shortness of breath, and even that is only on exertion, so scoring 1 out of 3. His psychological distress is mild, because, though he is sad and disappointed, he denies being distressed or anxious, giving a score of 1. His family distress is considerable, and although

they are engaging with counselling, it would rank as moderate to severe, scoring two to three. At most therefore, his scores could be around 6 even allowing for interrater variability. A score of 9 is excessive and incorrect.

3: This is a trick question. SAS scores were never intended to be amalgamated and given as a total score. The problem severity score is the one that's totalled and given.

4: No. the RUG-ADL is a measure of what the patient does and not what they are capable of doing. What they are capable of doing is reflected by the AKPS score. A patient may be capable or think they are capable of walking upstairs, however in reality they only move from the bed to the chair. The RUG-ADL measures this activity, not what they think they can do or what they can do when instructed to by an allied healthcare professional.

5: True.

Answers to Question 2:

F/T/F/F

1. False. Elizabeth is in the unstable phase. This is because she has had an acute change in her symptoms that require a change in her treatment plan. She was quite well earlier in the week and this change in her condition was not anticipated. Her functional status has indeed changed; however, this change is acute in nature and could be attributed to her acute symptomatology. In addition, the unanticipated change in her family's psychosocial distress requires a change in the plan of care. This would independently lead to Elizabeth being recorded as being in the unstable phase of illness.

2. True.

    1. Pain: 1 (mild),
    2. Other symptoms vomiting/ retching: 3 (severe), also constipation, dyspnoea,
    3. Psychological distress: 0,
    4. Family distress: 3,

    Overall: total score: 7/12.

3. False.

    RUG-ADL:

    1. Bed Mobility: 3,
    2. Transfers: 3,
    3. Toileting: 3,
    4. Eating: 1,

    Total RUG-ADL: 10/18.

4. False. There is no evidence to suggest that Elizabeth is in bed more than 50% of the time which is in-keeping with an AKPS of 40%. As she requires considerable assistance with ADLs and frequent medical care her AKPS is 50%.

Answers to Question 3:

F/T/T/T/F/T

1: False.

The problem severity score is a clinician-rated tool.

2: True.

The RUG-ADL measures what the patient functionally does regardless of what they say they are able to do.

3: True.

The gold standard for the SAS is that it is patient-rated, but the patient can be assisted by a family member or a healthcare professional.

4: True.

The phases are not sequential. Whereas a patient will not normally go from the terminal phase to the deteriorating phase, it is certainly possible.

5: False.

Often, although a patient is experiencing a symptom, they might not find it particularly distressing whereas something else that objectively may not seem significant to the clinician may be causing the patient severe distress. For example, a patient may have moderate pain (2/3 on the problem severity score scale), however they may not find it distressing (2/10 on the SAS). However, their lack of appetite could be very distressing for them (9/10 on the SAS), much more so than their pain.

6: True.

Answers to Question 4:

T/T/F/F/F

1. Pain=0, Other symptoms = 3 (severe dyspnoea), Psychological distress=3, Family and carer distress = 3, Total=9.
2. Bed Mobility =4, Toileting=5, Transfers=5, Eating=1, Total = 15.
3. False. Alex has scored his dyspnoea as severe and describes how distressed he is by his poor appetite as he clearly enjoyed both eating and blogging about food. It is very likely that if he understood the rating scale for SAS, he would have scored the distress/bother from each of these symptoms much higher. The scoring suggests that Alex does not understand how to score his distress using the SAS.
4. False, Alex's phase on admission is unstable as there is an acute and unexpected change in his condition and there is no care plan in place.
5. False, Alex is almost completely, but not totally bed bound. His AKPS is 30%.

Answers to Question 5:

Phase	RUG-ADL	PSS	AKPS	SAS (Patient-rated)	
Unstable	17/18	12/12	40%	Sleeping	6
				Appetite	0
				Nausea	2
				Bowels	2
				Breathing	9
				Fatigue	1
				Pain	8

Brendan's phase of illness is now unstable due to the advent of a rapidly worsening new unanticipated problem requiring an urgent change in the plan of care.

Due to his worsening condition his RUG-ADL has increased to 17/18 as Brendan requires the assistance of two staff for movement in bed (5), for toileting (5) in bed and would need the help of two or more staff to get out of bed (5). He is also unable to eat unaided (limited assistance i.e. 2).

Brendan's problem severity score has increased to 12/12 due to severe pain (3), other symptoms – severe dyspnoea (3), severe patient psychological distress (3) and severe family psychological distress (3).

He is currently too unwell to get out of bed but was out of bed for breakfast, so we score his AKPS at 40%, i.e. in bed more than 50% of the time.

Answers to Question 6:

Answer 6a: Stable. Aisling's problems and symptoms are adequately controlled by the established plan of care and further interventions to maintain symptom control and quality of life have been planned.

Answer 6b: Deteriorating phase, Aisling is suffering from worsening nausea

and new headaches that are not unanticipated in the setting of metastatic brain disease recently treated with whole brain radiation therapy. Her parents' distress is gradually increasing to the extent that it is impacting on the plan of care.

NB: It is important to stress that a patient may be in the deteriorating phase without a functional deterioration.

Answer 6c: Stable phase. Once again, her symptoms are controlled by the established plan and her family/carer situation is stable.

NB: It is possible for a patient's phase of illness to move to the deteriorating phase without always progressing on to the terminal phase.

Answers to Question 7:

1. False. This patient will score 3 as he or she relies on PEG feeding and is unable to administer feeds by him/herself.
2. False. This description is of a patient with an AKPS of 60%.
3. True. The learning point here is that although a patient may have more than one 'Other symptom' each scoring a different level of severity (1 mild, 2 moderate, or 3 severe), only the highest score for any one symptom is counted.
4. False. The SAS rates seven symptoms from 0 (absent) to 10 (worst possible distress). If a patient scores a symptom as 2 it is causing mild distress only. NB: The SAS scores are not to be totalled – each symptom rating stands on its own merits.
5. False. The team has responded to the patient entering the unstable phase and the new care plan seems to be working. However, the unstable phase does not end until the team has reviewed the care plan and confirmed that no further changes are required.

Answers to Question 8:

Answer 8a:

Phase	RUG-ADL	PSS	AKPS
Unstable	4/18	8/12	70%

Frank is in the unstable phase because he is experiencing a rapid increase in the severity of his pain and requires an urgent change in the plan of care as a result.

His RUG-ADL score is 4 because he is independently able to manage transfers, bed mobility, toileting and feeding, including managing his PEG feeding.

Frank has a problem severity score of 8 because he has severe pain (3); is severely fatigued (3) and moderately psychologically distressed (2). There is no family/carer distress (0).

NB: Though Frank complains of mild constipation, moderate nausea and severe fatigue, only the single highest scoring 'other symptom' is counted towards the total problem severity score.

As Frank can care for himself but is neither able to carry out normal activity nor do active work, his AKPS is 70%.

Answer 8b:

Phase	RUG-ADL	PSS	AKPS
Unstable	12/18	8/12	40%

Having been in the stable phase, Frank is now in the unstable phase as he experiences a new set of problems that require an urgent change in his plan of care.

His RUG-ADL has changed markedly as a result of his clinical deterioration and he now needs the physical assistance of one for bed mobility (3), for toileting (3) and for transfers (3). He requires full assistance with PEG feeding (3) resulting in a total RUG-ADL of 12.

Frank's problem severity score is now 8 – he has no pain (0), moderate dyspnoea (2), severe distress due to his hallucinations (3), while his family member has become very combative and distressed (3).

As he is spending more than 50% of the time in bed, Frank's AKPS is now 40%.

Answers to Question 9:

1. A, C, E
    a. While it might be tempting in order to save time and effort, please do take the time to record true PCOC scores for each 24-hour period.
    b. A patient's condition can of course change from one day to the next.
    c. If something like PCOC is worth doing (of course it is!!) it is worth doing properly.
    d. Naturally, it is important to be able to accurately record the effectiveness of the care we provide to our patients.
    e. The quality improvement and quality Assurance processes in your organisation will undertake regular audit and case review of your recording and use of PCOC data. The improvement, change & research cycle is a key component of PCOC strategy to embed and sustain PCOC in each organisation.
2. B, D
    a. A change in a patient's phase of illness (and change in plan of care) is one of the indications for re-scoring each of the five PCOC Clinical Assessment Tools. The others are on admission or day of first assessment, daily in the Specialist Palliative Care IPU setting (at each patient contact in the hospital and community settings) and at discharge.
    b. This is correct – the plan of care must be reviewed and confirmed that no changes are required before the patient can re-enter the stable phase.
    c. Though intuitively this seems the most likely clinical scenario, it is not always true. For example, a patient who is in the stable phase can suddenly become so ill that death is likely within days

without a need for either urgent or periodic review of the plan of care

d. This is a critical learning point and a fundamental tenet of the recording of phase of illness

e. A deterioration in a patient's overall functional status is only one of four indicators that may lead to a patient entering the deteriorating phase. The others are:

   i. A patient experiences a gradual worsening of an existing problem or

   ii. A patient experiences and new but anticipated problem or

   iii. Family/carers experience gradually worsening distress that impacts on the patient's care.

3. A, C, D

a. This is a proven outcome where organisations implement the PCOC cycle of routine assessment, measurement of patient outcomes, reporting and benchmarking to drive improvements in palliative care.

b. PCOC reports issue to participant organisations on a six-monthly basis.

c. Each organisation will know their own results and how they compare against PCOC benchmarks but will be unable to identify the results of any other organisation.

d. Yes, you can! Measurement of organisational performance against PCOC benchmarks provides valid evidence to support service development.

e. All three are recommended as the key components of a multi-pronged approach to successfully embed the assessment tools into routine practice.

4. A, B, C, E

   a. In routine use, PCOC data can become an integral component of all three processes.

   b. This is essential – the five PCOC Cinical Assessment Tools are intended for use where you meet the patient.

   c. Should occur at any change of a patient's care plan – this point is worth reiterating.

   d. This is not correct. If a patient is absent from the IPU for long enough that PCOC scores cannot be recorded for a given day, their episode of care must be closed on epiCentre. A new episode of care should then be opened upon the patient's return.

   e. This is true – there is a greater potential for assessments on the days of admission and discharge to be missed than on other days of inpatient stay.

5. B, E

   a. All five PCOC Clinical Assessment Tools are for use in all care settings.

   b. In the community setting, PCOC scores may be recorded during either a telephone or a face to face contact.

   c. A sudden change in a community-based carer's circumstances could suddenly impact on a patient's care to the extent that the patient can no longer be safely cared for at home. An urgent change in the plan of care would be required.

   d. In the community setting PCOC scores are recorded at each patient contact which may not necessarily be daily.

   e. As the carer is most likely spending more time with the patient than the community palliative care clinician, they are best placed to complete the SAS by proxy if required to do so on the patient's behalf.

Answers 10b:

T/F/F/T/F

1. T: Danny has developed a new and unexpected problem that requires a new plan to be put in place. Also, his family have arrived and are very upset and a new plan needs to be developed for this.
2. F: In the IPU setting, PCOC scores need to be recorded daily and at any phase change.
3. F:
    a. Pain: 3,
    b. Other symptoms: between falling due to loss of power, urinary retention requiring catheterisation, his other symptoms would score 3,
    c. Psychological distress: 3,
    d. Family distress: 3,

    Total 12/12.
4. True. Danny now requires considerable assistance and frequent medical care.
5. False. Danny's RUG-ADL has changed considerably to 16/18
    a. Assistance of two for transfers = 5,
    b. Assistance of two for bed mobility = 5,
    c. Assistance of two for toileting = 5,
    d. He is independent for eating still = 1.

Answers to Question 10:

Answers 10a:

F/F/T/F/T

1. F: Danny is in the stable phase as the team has a plan of care in place for him
2. F:
    a. Pain: 1,
    b. Other 2 (lack of energy),
    c. Psychological: 1,
    d. Family distress: 0 (As we cannot ascertain his absent family's distress it is scored as 0),

    Total Score is 4.
3. True. Danny is able to care for himself, but is unable to carry out normal activity or normal work.
4. As he says his pain doesn't bother him, his SAS pain score would be expected to be much lower. His SAS score for fatigue is appropriate though, as he says he finds this upsetting.
5. True, Danny is independently able to transfer, mobilise in bed, toilet and eat, scoring 1 for each, a total RUG-ADL of 4/18.

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