Health Learning Partnership
End of Life Care
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Case 1 – Malignant bowel obstruction

Sarah is a 43 year old woman colon cancer, diagnosed in 2014. She was hoping for a curative resection but recent imaging has confirmed multiple liver metastases and surgery has been abandoned. She is awaiting oncology review for consideration of palliative chemotherapy.

She has had a recent hospital admission with abdominal pain and was found to have a hydronephrosis, which has now been stented.

She has a partner, Samir and two children aged 6 and 8 years old. She works for the BBC but is currently on sick leave.

She has developed increasing abdominal pain, associated with nausea and anorexia. You are asked to review her at home.

Is this patient a surgical candidate?

Dependent on:

Performance status

Extent of disease, site(s) of obstruction

Patient's wishes and expectations

Assessment of malignant bowel obstruction

Determine likelihood of BO and exclude other causes

Metabolic abnormalities

Medication review

Nutritional / hydration status

Abdominal masses

Ascites

Faecal impaction

Clinical Features to determine type of obstruction

- **Type of cancer**
- **Abdominal pain**
  - Constant background
  - Colic
- **Vomiting +/- nausea**
- **Abdominal distension**
- **Absolute constipation or Diarrhoea**
- **Borborygmi, normal or absent bowel sounds**

Treatment options

Depend on:

- Performance status
- Extent of disease, site(s) of obstruction
- **Patient's wishes and expectations**

➢ **Implications of surgical intervention**

Hospitalisation, recovery time, stoma

➢ **Place of care**

Symptom burden, carer burden, hydration/nutrition

Management

- Try to anticipate and plan treatment in advance
- Surgical intervention should be considered in all patients
- Venting or stenting procedures less invasive options for some
- Medical management surprisingly effective

Medical Management

- **Appropriate drug regimen can provide excellent symptom relief**
- **CSCI is route of choice for most drugs**
- **IV fluids, NG tubes rarely needed**
- **Allow to eat and drink little and often**
- **Good mouth care vital**
- **Realistic goals**

Treatment - pharmacological

Approach dependent on nature of obstruction:

Drugs to encourage bowel transit (if partial / functional)

- e.g. metoclopramide, bowel softener, steroid

Drugs to act on the central nervous system to reduce nausea and vomiting

- e.g. cyclizine, haloperidol, levomepromazine

Drugs to reduce gastrointestinal secretions (if complete)

- e.g. hyoscine butylbromide / octreotide

Pain

Background pain

Opioids

Colic

May be relieved by opioids

Most need antispasmodic

- Hyoscine butylbromide 20mg stat and PRN
- Hyoscine butylbromide 60-120mg/24hr
- Also has an antisecretory action

Nausea and Vomiting

If no colic and passing flatus try prokinetic

Metoclopramide 40-100mg/24hr

Stop if develop colic

If patient has colic prokinetics are contraindicated

Cyclizine +/- haloperidol

Avoid using metoclopramide and cyclizine together

Somatostatin Analogues

- **Octreotide inhibits secretion of numerous hormones**
- **Resultant reduction in volume of GI secretions**
- **More rapidly effective than hyoscine**
- **Duration of action 8 hours**
- **Administer via CSCI or SC bolus**
- **Side effects: dry mouth and flatulence**

Laxatives

- **Stop stimulant, osmotic or bulk-forming laxatives**
- **If likely to be constipated try phosphate enema and a softener e.g. docusate sodium 100-200mg bd**

Corticosteroids

Cochrane review 1999 (Feuer and Broadley)

May relieve peri-tumour oedema

Resultant improvement in symptom control

Trial of dexamethasone

- 8mg daily SC
- Review after 5-7 days
- Stop or reduce dose according to response
- Be aware MAY drive appetite

Case 2 - Agitation

Tom is a 52 year old lawyer, who underwent resection of a glioblastoma multiforme two months ago. He is due to start consolidation chemoradiotherapy this week. He is on a reducing dose of dexamethasone and is taking morphine MR 20mg bd for headaches.

He lives with his wife and 15y old twin sons. Over the last week, his wife has noticed a change in Tom's behaviour. He has been irritable and verbally aggressive at times, directing threats towards his wife. He seems to be having difficulty reading a paper and using his phone. He remains mobile and fully independent.

His wife requests an urgent visit, as Tom's behaviour is escalating and this morning he has smashed his iPad.

Definitions

Delirium:

A transient organic brain syndrome

Criteria include:

- Change in cognition
- Disturbance of **consciousness**
- **Acute onset** and fluctuating pattern
- Associated with general medical condition, substance intoxication/withdrawal

Agitation:

Mental state of extreme emotional disturbance

Causes of agitation

Delirium

Anxiety

Depression

Acute adjustment reaction

Anger / Fear / Fright

Pain

Brain disorder (malignancy)

Psychiatric illness (including dementia)

Terminal agitation

Assessment part 1 – the patient

- History/Examination of the patient in their current setting
- Previous history / pattern of behaviour
- Assessment tool for confusion e.g. AMT(4), 4AT, CAM
- Tests – bloods / XRs etc.

Assessment part 2 – the context

- **Context – current environment**
- **Context – staffing /other patients**
- **Context – family concerns / wishes**

- **Expectation – of ALL concerned**
- **Availability of other resources**
- **Risk management – to patient and others**

Management

- **Can we reverse the cause/s?**
- **If we can – how simply?**
- **What about capacity/consent?**
- **If capacity is an issue – who else do we need to consult?**
- **Do we need some temporary sedation?**

Two step functional test of mental capacity

Step 1:

Disturbance or impairment in functioning of the mind or brain

Step 2:

Impairment sufficient to lack capacity to make a specific decision:

- Inability to understand information
- Retain the information
- Weigh it up
- Communicate a decision

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Risk Management

If we can't reverse the cause/s:

What about simple things – a clock, familiar objects, privacy or company, light or dark, music, conversation, chair rather than bed, an open door etc. etc.

What are reasonable and proportionate steps to mitigate potential risk?

Risk Management

- When do we want to treat with drugs and why?
- When do we need to consider move to a more controlled setting?
- The treatment plan needs to be clear, consistent and well documented
- How do we put the plan into action and ensure adherence to it?
- What legal framework needs to be in place to support management?

Drugs - 1

- **What is readily available?**
- **How can it be given?**
- **Who can/will give it?**
- **How long do we expect it to last?**
- **What is our measure of 'success'?**
- **Who can review this and when?**
- **What will we do NEXT?**

Drugs - 2

Atypical anti-psychotics e.g. risperidone

Typical anti-psychotics e.g. haloperidol, levomepromazine

Benzodiazepines e.g. lorazepam or midazolam

Phenobarbitone (SC in severe cerebral agitation and/or fitting)

Drugs - 3

Set yourself (and others) realistic expectations – inc. time scale

Have a CLEAR PLAN

Define success AND failure

Avoid repeating a failed dose and define when the drug has failed

Don’t hesitate to ASK for further advice and support

Case 3 - MSCC

Neil is a 58-year-old man with cholangiocarcinoma and spinal metastases. He has been experiencing severe pelvic pain for several months. During a recent hospital admission, he received radiotherapy to his sacrum but this has not improved his pain. Due to negative experiences during his last admission, Neil is adamant that he does not wish to return to hospital.

His wife requests a visit. Neil has been up all night with a severe, unremitting pain radiating down both legs. The pain is worse when he bends over or coughs. He has taken three doses of oxycodone IR, which makes him drowsy but offers little pain relief.

Malignant spinal cord compression

An oncological emergency

The earlier definitive treatment is commenced to relieve the compression and any nerve damage, the better the functional outcome is for the patient

5% of patients with terminal cancer will have MSCC in last 2 years of life

Presenting symptom of cancer in 20% of cases

Commonest in prostate, breast and lung cancer

Early detection

Early detection can preserve or restore function

Inform patients about red flags

Pain is the most common FIRST symptom

A normal neurological examination does NOT exclude a diagnosis of MSCC

30-50% of patients show multi-level involvement, so whole spine imaging is imperative

Red flag symptoms

- progressive pain in the spine
- severe unremitting spinal pain
- spinal pain aggravated by straining (for example, when passing stools, when coughing or sneezing, or when moving)
- pain described as 'band like'
- localised spinal tenderness
- nocturnal spinal pain preventing sleep
- neurological symptoms: radicular pain, any limb weakness, difficulty in walking, sensory loss, or bladder or bowel dysfunction

Spinal mets or MSCC – when to refer to MSCC coordinator (NICE)

Immediate referral

- Neurological symptoms (including radicular pain, ANY limb weakness, difficulty in walking, sensory loss, any bladder or bowel dysfunction)
- Neurological signs of spinal cord or cauda equina compression

Urgent referral (in 24h)

- Pain in thoracic or cervical spine
- Progressive lumbar pain
- Severe unremitting lumbar pain
- Spinal pain aggravated by straining
- Localised spinal tenderness

Should we investigate?

Indications to avoid investigation :

- Poor baseline performance status
- Well established paralysis of more than one week
- Predicted lifespan of only days to weeks

National audit of MSCC in Scotland

- In over 300 patients with MSCC, the average survival after cord compression was 60 days, although one in eight patients survived up to one year.
- Survival longest in those who could walk at the time the spinal cord compression was diagnosed.
- Shortest survival associated with more aggressive cancers, e.g. lung

Whilst awaiting diagnosis

Analgesia

Rest and immobilisation

Consider catheterisation

Steroids

- Immediate loading dose of 16mg dexamethasone unless contraindicated
- Avoid if lymphoma suspected

Case 4 – cancer pain in opioid dependence

Clare is a 54-year-old woman with unresectable pancreatic cancer. She has a history of alcohol dependence, IV drug use and is hep C positive. She is a victim of domestic violence and it is suspected that her partner is still a drug user. She is on maintenance methadone treatment.

Her daughter phones the surgery very distressed as Clare is in severe pain. She has disclosed to her daughter that she smoked heroin two days ago. She is also taking morphine MR 300mg bd and a colleague has flagged concerns about her frequent requests for Oramorph. In addition, she takes methadone 22mg once daily.

A nurse from the hospice visited her at home last week. At that time she expressed a wish to receive all active treatments and became very upset when DNACPR was mentioned.

Assessment and management principles

Accept and respect the report of pain

Take a substance abuse history

Complete a pain assessment & use the principles of the World Health Organization "Analgesic Ladder"

Apply appropriate pharmacological principles when using opioids

- Use adequately titrated doses (consider tolerance / no pharmacologic ceiling)
- Use regular dosing schedule, at appropriate intervals, for constant pain. **Avoid PRN dosing.**
- Plan carefully with patient when route of administration is changed or opioids withdrawn

What if the patient is on methadone?

If the patient is on a methadone programme

- the dose of methadone should not be altered and the appropriate opioid for pain control should be added.
- differences in the use of methadone for pain and in the management of substance misuse are marked and therefore should be left alone.

Support the patient maintain control

Consider brokering a contract

- Detail expectations and define limits of acceptable behaviour
- Agree rules regarding prescription renewals, lost, stolen or altered prescriptions
- Set limits: urine toxicology screens; tamper proof infusion pumps; restriction of visitors; frequent visits; limit supply of medication

Managing patients in the community

- **Do not visit alone if there are concerns about behaviour**
- **Use single point of prescribing**
- **Prescribe analgesics weekly or even twice weekly**
- **Be willing to prescribe additional medication if disease progressing, pain is worsening or patient developing tolerance**
- **Ensure Out–of-Hours provider is aware of substance abuse issues to prevent additional prescriptions being made**
- **Consider admission to specialist care if significant dose changes or analgesic requirements are escalating rapidly, particularly at high doses**

Drug diversion

Be aware of friends or family members who may try to buy or steal prescribed drugs.

Removal of drugs from a patients home:

- after death, all drugs are the property of the deceased's estate
- they should be returned to a pharmacy for destruction by a family member
- if removal by a health care professional is required, the local PCT policy should be followed.

If a healthcare professional is concerned about the presence of illicit drugs in a patient's home, it may be appropriate to contact the police.

Support the patient maintain control

Set realistic goals for pain therapy

Know the limitations, anticipate problems and avoid excessive negotiation

Educate and support staff avoid discriminatory behaviour

The care of the substance abusing patient with pain requires a team effort

Early consultation with psychiatry, substance abuse, pain specialists, etc.

Evaluate and treat other distressing physical and psychological symptoms

Constantly assess and re-evaluate the effects of pain interventions

2015 Joint statement on DNACPR – post Tracey

Emphasises:

- the importance of **involving people** in the decision-making process
- where CPR has **no realistic chance of success** it may involve informing people of the decision and explaining the basis for it
- whenever possible, anticipatory decisions about CPR are best made well in advance
- such advance decisions are often best made **as part of a broader consideration** of the type of care or treatments a person would wish to receive

https://www.youtube.com/watch?v=ImrfD4RbMDE

https://www.youtube.com/watch?v=liyCebOTl5c

Final thoughts