Palliative care in end-stage renal disease

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Inhoudsopgave

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Summary

The recommendations in this guideline on palliative care in End-Stage Renal Disease (ESRD) aim to improve the quality of patient care and counselling. The guideline is predominantly based on scientific research and consensus.

How palliative care is incorporated into nephrology practice

- Focus on all dimensions of palliative care: physical, psychological, social and spiritual. Provide basic care in all these areas. If necessary, consult experts or make referrals.
- Discuss patients' health problems, worries and wishes regularly, elicit preferences and changing life goals of family and close friends.
- Personalize care and treatment plans based on patients` individual goals, aspirations, needs and limitations.
- Anticipate future problems (including discontinuing dialysis). Consider barriers in care delivery such as language differences, level of literacy and cultural differences.
- If necessary employ a professional interpreter, or where possible encourage a friend or family member to act as an interpreter.
- As new complications arise, or when patient's condition worsens, ask yourself if you would be surprised if the patient will die within a year ('Surpise Question').
- If death is anticipated within a year, discuss potential scenarios and advanced care planning (ACP). Establish patient's wishes, needs, fears and expectations concerning the end of life, including discontinuing dialysis.
- Discuss symptoms and symptom management and how they affect physical, psychological, social and spiritual functioning.
- Identify the informal caregivers, establish the needs and preferences of both patient and informal caregiver and where possible give regular updates.

Within the guideline working group consensus has been reached that the multidimensional approach which is propagated in the WHO's definition of palliative care, is equally applicable to patients with ESRD whose estimated life expectancy is more than one year.

The decision not to start dialysis or to discontinue dialysis

- Ensure a careful decision-making process. If the decision either not to start or to discontinue dialysis is taken, discuss the expected course of the illness and its accompanying symptoms.
    - If the decision either not to start or to discontinue dialysis is taken, discuss the following: life expectancy, symptoms, medication, diet and fluid intake, procedure concerning resuscitation and, if relevant, ICD, psychosocial counselling, legal representative, legal regulations, desired place of death and decisions concerning the end of life.
- Ensure that primary care is informed promptly of the care plan, both orally and in writing.

In the event of conflicts concerning not starting or discontinuing dialysis

- Follow the methodology of shared decision-making. If this does not result in consensus, enquire about the motivation of the patient by means of a step-by-step discussion method.
- If necessary, involve external health care professionals.
- Consider a 'time-limited trial period' of dialysis.

Advance care planning (ACP)

- Start structured patient-oriented ACP, preferably at an early stage in patients:
    - >75 years
    - of whom their treating physician would not be surprised if the patient will die within a year ('Surprise Question')

    - who have a Charlson Comorbidity Index ≥6 or ≥5 with hospital admission in the preceding 6 months
    - who do not wish to start or wish to stop dialysis
    - who wish to discuss ACP
- As treating physician, take the initiative to discuss ACP.
- Discuss matters relevant to the patient such as reasons not to start dialysis or to discontinue it, resuscitation policy, last will desired place of death and decisions concerning the end of life. Document discussions and decisions in the patient's chart .
- Evaluate the ACP decisions at least once a year.

Sleep disorders

- Evaluate the cause of the sleeping problem and, if possible, treat it.
- Start with non-pharmaceutical interventions.
- If sleeping problems are severe, or if there is an acute indication for treatment or if life expectancy is <4 weeks, choose a benzodiazepine agonist (zolpidem 5-10 mg or temazepam 10-20 mg), in other cases prescribe 3 mg melatonin. As the physiological melatonin peak varies between individuals, the optimal dosage of melatonin and the optimal time for administration may differ per patient.
- If this is insufficiently effective, consider adding a sedating antihistamine or a sedating antidepressant or antipsychotic. Be aware of anticholinergic side-effects in older patients (delirium in particular).

Nociceptive pain

- Start paracetamol at a dosage of up to a maximum of 1000 mg 4/day, orally or rectally.
- Chronic use of NSAIDs (>2 weeks) is not recommended.
- If paracetamol is insufficiently effective, start transdermal fen tanyl (12 µg/hour). Alternatives are low-dosage SR hydromorphone, SR oxycodone, tramadol and transdermal buprenorphine. The use of codeine and morphine is not recommended.
- In unpredictable breakthrough pain, preferably give a fastacting fentanyl preparation, and in predictable breakthrough pain, IR hydromorphone or oxycodone or a fast-acting fentanyl preparation. Take into account the time that is necessary for the pain-relieving effect to occur.
- Only implement opioid rotation if the effect is insufficient and/ or if the strong opioid agent has unacceptable side effects.
- Note that laxatives should be prescribed in combination with opioids.

Neuropathic pain

- Start low-dosage pregabalin (25 mg 1/day) or gabapentin (100-300 mg every other day).
- If insufficiently effective, consider treatment with a tricyclic antidepressant (nortriptyline or desipramine) or an SNRI (venlafaxine or duloxetine).
- If necessary add a strong opiate agent (in combination with a laxative) as in nociceptive pain.

Mixed nociceptive and neuropathic pain

- Start with a strong opioid agent (in combination with a laxative), as in nociceptive pain.
- If ineffective, add pregabalin or gabapentin.

Dyspnoea

- In dyspnoea due to hypervolemia in patients who are not or no longer being dialysed but still have some residual diuresis, start with high doses of loop diuretics or consider single isolated ultrafiltration in patients who discontinued dialysis.
- Start with a strong opioid agent (in combination with a laxative), as in nociceptive pain.
- In acute dyspnoea give a fast-acting fentanyl preparation or an IR opioid (hydromorphone, oxycodone). In case of incidental administration IR morphine orally, or SC or IV can be given.

Itching

- Start with a neutral, emollient cream.
- If insufficiently effective, treat with gabapentin (100-300 mg 1/day) or pregabalin (25 mg 1/day).

Restless legs

- Give advice on lifestyle: good sleep hygiene, limit caffeine and alcohol intake, stop smoking, take plenty of exercise, cold and warm foot baths.
- If this is insufficiently effective, treat for a trial period with ropinirole (0.25 mg to maximum 1.5 mg, 1/day).
- If insufficiently effective, consider treatment with gabapentin (100 mg 1/day).

Delirium

- Evaluate the factors that provoke and contribute to delirium (somatic, medicinal) and treat these if possible.
- Always start with non-pharmaceutical interventions.
- Only start pharmaceutical treatment for delirium if other treatments for delirium have not been successful and/or if unwelcome symptoms such as agitation and signs of psychosis occur.
    - Start haloperidol (0.5-2 mg).
    - If agitation persists, give lorazepam (0.5-2 mg).
    - If haloperidol is contraindicated or if it has adverse effects, choose a low-dosage atypical antipsychotic (risperidone (0.25 mg), clozapine (6.25 mg), olanzapine (2.5 mg)) as an alternative to haloperidol. In Parkinson's disease or Lewy body dementia, clozapine is the drug of choice.

Depression

- Treat predisposing factors such as uncontrolled pain, treat comorbidity or change medication that has a negative effect on mood.
- Always offer counselling sessions with specific attention to emotional, behavioural and social aspects.
- In the event of an adaptive disorder or a depressive disorder, consider referral to a mental health psychologist, clinical psychologist and/or a psychotherapist for specific psychotherapy.
- In a depressive disorder, consider medicinal treatment 1. sertraline (25 to a maximum of 200 mg) or citalopram (20 to a maximum of 40 mg). 2. mirtazapine (15 to a maximum of 45 mg).