Diagnosing dying

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Overview

- “Diagnosing Dying” what do we mean?
- Signs of dying
- Three illness trajectories
- Barriers to diagnosing dying
- The multi-disciplinary approach
- Communication
- Scenarios

Discuss

- What do nurses see in patients that makes them think they may die in a few days?

“Nurses often perceive signs and symptoms of dying that may mark the dying phase before physicians do, because of the intensity, frequency, and duration of their contact with patients and relatives”

(Gertrud, FM, et al, 2012)

Signs of dying

- Withdrawal from the world
- Reduced cognition
- Profound weakness – reduced level of function
- Reduced levels of consciousness
- Retained bronchial secretions
- Terminal restlessness
- Poor appetite, diminished intake of food and fluids
- Respiratory changes
- Difficulty swallowing medications
- Peripheral cyanosis
- Temperature changes at extremities

- Once you see the signs that a patient/resident may be dying what do you do next?

- Discuss.....
Diagnosing Dying

• Diagnosing dying is the recognition that a person is in the last days/hours of their life. Sometimes referred to as actively or imminently dying

• This is the time that the MDT review the patient and the plan of care as the focus of care may need to change to meet the needs of the patient and their family

• The LCP is recognised as an evidenced based gold standard care pathway for dying patients

Diagnosing dying is complex

• Uncertainty is an integral part of dying. Patients can live longer or die sooner than predicted

• Patients with chronic non-malignant conditions can come close to death on several occasions before they die

• Death can be viewed as a failure especially in the acute setting where the focus is diagnosis, treatment, cure

Barriers to diagnosing dying

• Hope that the patient may get better
• No definitive diagnosis
• Pursuance of unrealistic or futile interventions
• Disagreement about the patient’s condition
• Failure to recognise key symptoms and signs
• Poor ability to communicate with the patient and family
• Concerns about withdrawing or withholding treatment
• Concerns about resuscitation
• Cultural and spiritual barriers
• Medico legal issues

What are the barriers to diagnosing dying in the acute setting, residential care and the community?

Dying in NZ

• 85% die of a chronic illness, not a sudden event

• 50% of people near death are not in a position to make their own decisions

• There is a lack of good quality data on the place of death of those who die in NZ

• In Residential Care Facilities, 20% of new residents die within 3 months, 40% within 1 year

When we become ill many of us are unaware just how seriously and irreversibly sick we are: it is not uncommon to face death unknowingly or unaware that it is not an optional extra

(Adler, Jonathan. 2009)

(Elershaw & Ward, 2003).
Progressive chronic illness

Three most common trajectories identified

- Short Period of evident decline - Cancer
- Long term limitations with intermittent serious episodes - Heart Failure & COPD
- Prolonged Dwindling - Dementia/frailty

(Murray, Kendall, Boyd & Sheikh, 2005)

Malignant Conditions

Short period of evident decline - more predictable terminal phase

Most weight loss, reduction in performance status and impaired ability for self care occurs in patients last few months.

(Murray, Kendall, Boyd & Sheikh, 2005)

Long term limitations with intermittent serious episodes

- Deterioration associated with increased episodes of uncontrolled symptoms or unpredictable event - infection, arrhythmia
- Often results in hospital admission
- Patient’s function can decline with each episode
- May not respond to treatment
- Death can be sudden

(Murray, Kendall, Boyd & Sheikh, 2005)

Organ Failure

- Can succumb to minor physical events
- Signs of dying can include:
  - Pain, dyspnoea, respiratory congestion, delirium, dysphagia, fever and muscle twitching

(Murray, Kendall, Boyd & Sheikh, 2005)

Frailty and Dementia

- Can succumb to minor physical events
- Signs of dying can include:
  - Pain, dyspnoea, respiratory congestion, delirium, dysphagia, fever and muscle twitching

(Murray, Kendall, Boyd & Sheikh, 2005)

These patients already have a low baseline of cognitive or physical functioning
- Often reside in residential care facilities

Clinical Indicators for terminal care (Boyd & Murray, 2010)

1. Could the patient be in the last days of life? (signs of dying)

2. Was the patient’s condition expected to deteriorate in this way?

3. Is further life-prolonging treatment inappropriate? - Is further treatment likely to be ineffective or too burdensome, patient or EPDO has refused further treatment or valid advance directive

4. Have potentially reversible causes of deterioration been excluded? (infection, dehydration, bleeding, acute renal impairment, drug toxicity).
Interventions and Treatments?

Invasive procedures, investigations and treatments are often continued at the expense of comfort for the patient.

“We’ve got so many treatment possibilities that you can overuse them when the patient is dying.”

(Dr Barry Snow, Listener July 9th 2011)

Communication vital

- Important to ensure that end-of-life decisions are consistent with patient’s and families values and goals
- Late decision making for whatever reason reduces patient autonomy and quality end of life care for the patient and family

MDT Review and Discussion

- Clinical judgment, weighing up a complex mix of pathology, clinical findings, therapeutic responses, co-morbidities and psychosocial issues
- Important that the team agree that the patient is dying- otherwise variable management and contradictory advice

Communication with the Patient & Family

- Their understanding of what is happening.
- The dying process (leaflet)
- The plan of symptom management and care
- The goal of the plan of care is on maintaining patient comfort and dignity in the last hours or days of life
- Identify what is important to the patient and family
- The quality of communication with the family influences the perceived quality of the patient’s death

What if the patient’s condition improves

- This can happen as dying can be difficult to diagnose
- Important to review the dying patient regularly
- Consider the question- Is the patient actively dying?
- Communication with family
- Review care plan -LCP discontinued if no longer appropriate
- Ensure a palliative approach continues as part of the plan of care

(Ellershaw & Ward, 2002; Al-Quraeey, et al, 2009)
Scenario One - Residential Care

- Mrs Brown has a history of congestive heart failure, frailty, osteoporosis, frequent falls, mild cognitive impairment. Her advanced care plan indicates no active treatment or transfer to hospital.
- It is Friday, 1500 hours and the care assistant reports that Mrs Brown has refused lunch, is sleepy and declining fluids.
- RN assessment: Mrs Brown is febrile, tachypnoeic, ↓ consciousness, chest moist & restless.

You are the RN working with the caregiver - what do you do?

Scenario 2 - Acute Setting

- Mr Woodley is 72 years old with a history of COPD, frailty, benign prostatic hypertrophy and was admitted to the ward with pneumonia.
- He has lived with his daughter since his wife died 18 months ago.
- He’s had 2 admissions to hospital in the past 3 months with breathing difficulties and end-stage COPD.
- He has a NFR order and has openly admitted that he wants to die. His daughter is aware of this.
- He develops respiratory failure, the registrar wants to admit him to ICU for intubation & ventilation. His daughter is upset and questions the management.

Discuss in small groups - what you think should happen.

Summary

- Decline in patients condition leads to MDT review.
- MDT assessment of current symptoms and reversible causes for the decline considered and addressed.
- Communication and agreement within the MDT that the patient is in the last days of life.
- The importance of health care providers communicating effectively the options available to the patient and family.
- Listening to the patient and families needs, goals and wishes and planning appropriate end-of-life care.

(Ellershaw & Ward, 2003; Al-Quarry, Collis & Feuer, 2009)

References


References