Palliative care in stroke

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Topics

Stroke.

Palliative Care Needs of Stroke Patients.

Nutrition in Severe Stroke Patients

Withdrawal of Treatment.

Case scenario.

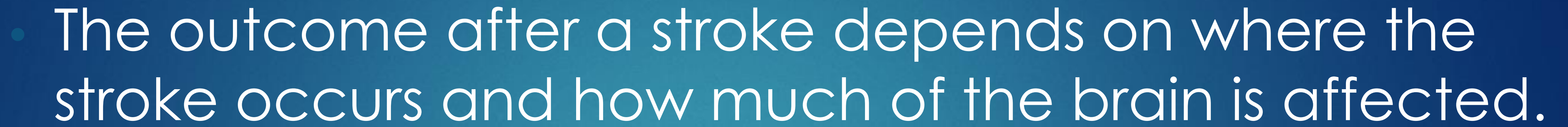
Summary

Questions.

Stroke

A **stroke** is a condition where a blood clot or a ruptured blood vessel interrupts blood flow to an area of the brain.

A lack of oxygen and glucose flowing to the brain leads to the death of brain cells and brain damage.



- The outcome after a stroke depends on where the stroke occurs and how much of the brain is affected.

- Smaller strokes may result in minor problems, such as weakness in an arm or leg.
- Larger strokes may lead to paralysis or death.

Defining our Patient Population

- Acute Stroke patients (within a month) VS Late Stroke patients (over a month)

- Stroke in young vs Stroke in old age

How Common Is It ?

- 10% of all deaths worldwide in 2002
- 5-year mortality 40- 50%

2010 US Statistics

- 130,000 stroke-related deaths contributing to over 5% of all deaths in the US
- **50% of deaths occur in hospitals (including EDs and acute rehab. facilities)**
- **35% occur in nursing homes**
- ***15% occur in the home or other places***

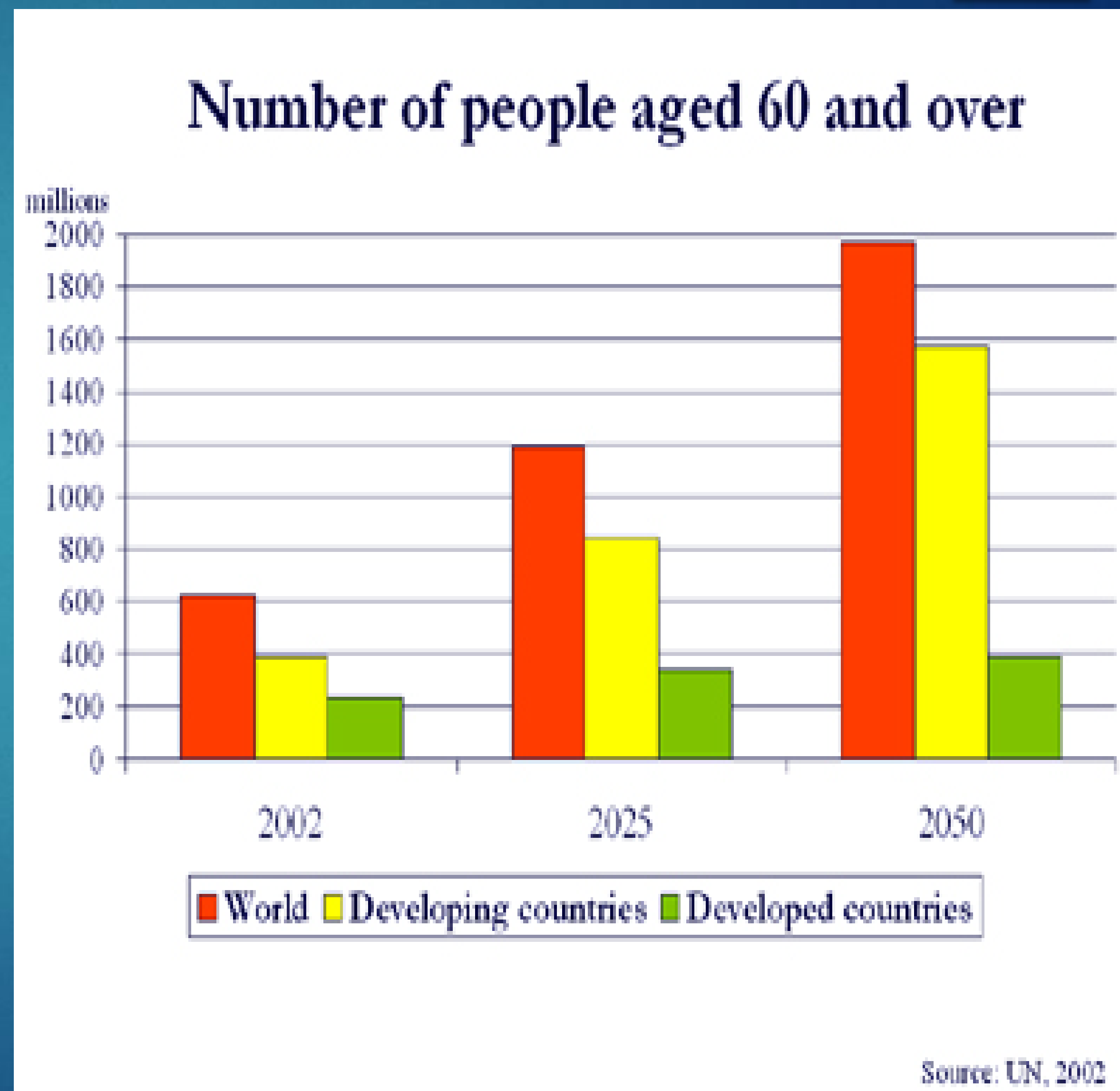
National Clinical Guidelines for Stroke in UK (2004, updated in 2007)

- It is the third most common cause of death in the UK, with 26,400 people dying each year, and direct costs to the NHS of around £2.8 billion.
- **All stroke patients should have access to specialist palliative care expertise.**
- **All staff providing this care should have appropriate training.**

International Perspective

- In last four decades:
  - 42% decrease in stroke in high-income countries
  - more than 100% increase in low to middle income countries.

(Feigin, Lancet Neuro, 2009)



Objectives

- Strategies to deal with symptoms at end of life for stroke patients
- To gain an approach to prognostication at end of life for stroke patients
- To help determine goals of care at end of life – including intubation/extubation and tube-feeding

Palliative care in acute stroke: What are the issues?

- Stroke results in **high levels of *mortality and morbidity***, and can cause a wide range of distressing symptoms and problems.
- Patients with stroke and their families face **major challenges in the initial period**
- **Certain treatment decisions raise *complex ethical dilemmas***
- Family members face considerable ***uncertainty*** and have support and information needs

No mention of the word "terminal".

This suggests that palliative care has a role where there is a risk of death but no certainty that the patient will die.

Reference is made to the need for early intervention.

- The needs of stroke patients who die in the acute phase are different to those who's death occurs at a later stage.

CHALLENGES

1. Defining the dying stage in patients with stroke.

   Identification of end of life care needs is likely to run parallel with assessments of the patient's functional status.

2. Even when both medical and nursing staff feel that a patient might have palliative care needs,
   referral to a specialist palliative care service can be seen as inappropriate.

3. Stroke is by definition a condition that occurs suddenly,
   often leaving the patient with communication problems,
   due to decreased consciousness and speech problems.
   Therefore, end of life decisions are often made on behalf of the patient

When to call in the Palliative Care Service?

Symptom management.

Ethical dilemmas.

Communication.

How are decisions made?

Multidisciplinary context.

Involve the patient and family.

Have the patient's best interests at the fore.

Patient's wishes should be respected.

WHAT ARE THE PALLIATIVE CARE NEEDS OF STROKE PATIENTS?

Table 2 Symptom prevalence in the 42 patients

Symptoms	*n* (%)
Dyspnoea or dyspnoea behaviour(s)	34 (81)
Pain or pain behaviour(s)	29 (69)
Mouth dryness	26 (62)
Constipation	16 (38)
Anxiety, sadness	11 (26)
Delirium	6 (14)
Sleep disorders	5 (12)
Other symptoms	5 (12)

n, number of patients

Dyspnoea or dyspnoea behaviours

- Wheezing
- Laboured breathing
- Noisy respiratory tract secretions (death rattle)
- Tachypnoea
- Use of accessory respiratory muscles

Pain and discomfort or pain and discomfort behaviours.

- Pain score > 2.
  Headache, central post stroke pain, co-morbidities e.g. arthritis.
- Sad facial expressions.
- Negative verbalisations.
- Rubbing of the body.

NB – ***Risk of under recognition in non-verbal patients***.

Depression and anxiety.

50% low mood, anxiety or confusion.

20% expressed ***"life is not worth living".***

High levels of post stroke depression – 30%

NUTRITION

Experience of hunger and thirst are difficult to establish after a severe stroke.

- *Oral fluid and nutrition is part of core care and should not be withdrawn unless the patient refuses or is unable to participate.*

- *Clinically assisted nutrition and hydration are considered medical treatments and can be withheld or withdrawn if considered to be of no benefit to the patient.*

What are the risks of clinically assisted nutrition and hydration?

- Tube displacement.
- GI intolerance.
- Reflux.
- Increased secretions.
- Aspiration pneumonia.
- Pulmonary oedema
- IV site infections.

Tube Feeding in Stroke

- No significant differences in mortality outcomes between early enteral tube feeding or not
- No excess pneumonia in early tube feeding
- Small apparent improved survival offset by 4.7% excess of survivors with poor outcome and worse quality of life

- "Thus, early feeding may keep patients alive but in a severely disabled state when they would otherwise have died."

(Donnan, *Lancet*, 2005)

Communication regarding prognosis.

Communication ***between patients, family members and professionals*** was consistently highlighted as central to a positive experience of stroke.

Accurate prognostication– **uncertainty is inevitable**.

Honesty and clarity of information is required even when prognosis is bleak.

When there is a shift in focus from active intervention to ***supportive care families want to be included in dialogue with professionals***.

Poor prognostic indicators:

- Advanced age.
- Severity of the stroke.
- Elevated BP, Blood Glucose, Temperature.
- Seizures.

Withdrawal of Treatment

Dynamic and evolving situation.

Discussion regarding futility of treatment.

Anxiety of family and staff regarding withdrawing life-sustaining treatment.

Anxiety:

Complex issues must be understood and documented.

Often easier to understand not starting treatment as opposed to withdrawing it.

No fully accurate method of predicting outcome after a severe stroke.

Decision with the Consultant.

Do Not Resuscitate.

Different to withdrawing medical support.

Should not influence treatment including admission to stroke units.

Should not influence nursing care provided.

Clear information reduces confusion among multidisciplinary team members and the family

Objective1.

List strategies to deal with symptoms at end of life

1. Case Study

- Mr. B – 79 y.o. male with dementia
- Slumped over unconscious while eating breakfast at nursing home
- CT shows large ICH with intraventricular extension
- Pt. unconscious, admitted to ICU, intubated
- Appears comfortable, extubated
- Family requests palliation

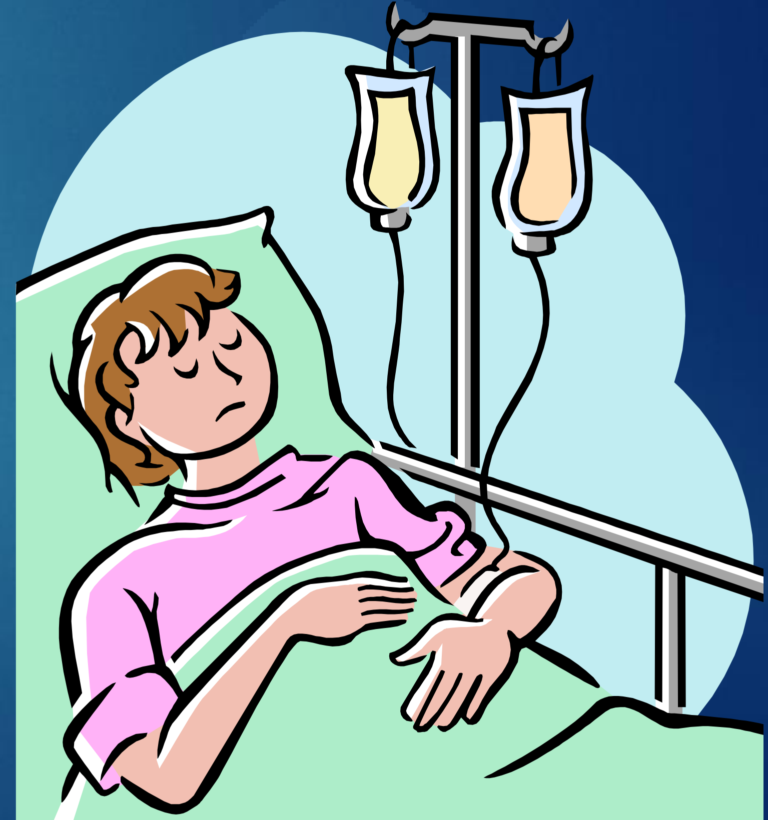
- ***What symptoms is he likely to experience ??***
- ***What medicines do you prescribe ??***

Symptoms of Acute Life-Ending Stroke

- May be asymptomatic

  Or

- Can have pain, restlessness /delirium, dyspnea, upper airway congestion



Palliation For the Minimally Conscious Patient Need Only 4 Drugs

Medication Class	Symptoms Treated	Drugs and Starting Doses
Opioid	Pain and/or Dyspnea	Morphine 2.5 – 5 mg subcut q1h prn OR Hydromorphone 0.5-1 mg subcut q1h prn
Neuroleptic	Delirium and/or Nausea	Methotrimeprazine 6.25-12.5mg subcut q4h prn OR Haldol 1-2 mg subcut q4h prn
Benzodiazepine	Delirium and/or Dyspnea	Lorazepam 0.5-1mg subling q4h prn OR Midazolam 2.5-5 mg subcut q4h prn
Anticholinergic	Upper Airway Secretions (Death Rattle)	Glycopyrrolate 0.2-0.4 mg subcut q2h prn OR Scopolamine 0.3 -0.6mg subcut q1h prn

Objective 2.

To Gain an Approach to Prognostication at End of Life for Stroke

2. Case study.

Mrs. L. 82 y.o. - large Lt. intracerebral hemorrhage, intubated in ER

CT shows intraventricular extension and midline shift

Pt. moving Lt. arm towards face, eyes closed, nonverbal

Getting progressively less responsive since extubation an hour ago

Family wants comfort care only

What is her Prognosis??

Intracerebral Hemorrhage (bright white area) CT Scan Slice of Brain

Daughter of stroke patient, 46 yrs

"I think my mum is dying, or it is the beginning of the end. My mum is 82. I just want her to have a quiet, peaceful, pain free, dignified death. They said there had been a very severe bleed and they were not expecting her to recover. It was handled very calmly and very sensitively".

Problems at End of Life for Late Stroke Patients

- Uncontrolled symptoms
  - Pain
  - Incontinence
  - Confusion (Delirium)
  - Low mood
- Lack of holistic care
- Ongoing difficulty with ADLs

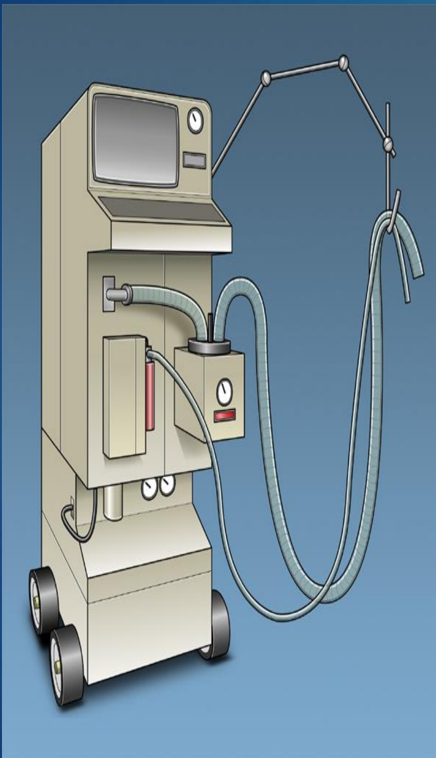
Identifying End of Life in Stroke patients

- Bedridden, profoundly weak
- Drowsy, poor attention span
- Take only sips of fluid
- Unable to take tablets
- Semi-comatose

Problems

- Changes difficult to identify
- Changes may not be irrecoverable
- Suggestions:
  - Functional deterioration
    - change - not static disability
  - Worsening comorbidities
  - Rate of change best prognostic indicator

Mechanically Ventilated Stroke Patients



Inpatient mortality 55% (48%-70%).

- 30-day mortality 58% (46%-75%)
- 1 -2 year mortality 68% (59%-80%)

(Holloway, *JAMA*, 2005)

Survival post extubation:

- 25% die within an hour
- 69% die within 24 hours
- Median duration 7.5 hours
- Majority experience agonal/labored breathing following extubation

(Mayer, *Neurology*, 1999)

Management After Ventilator Withdrawal

- Dyspnea
  - Opioids significantly decrease tachypnea
  - No change in Sa02, PaCO2 and pulse rate
  - No statistical association between escalating opioids post vent withdrawal and time of death
  - (Clemens, *J Pain and Symp Manage* 2007 and Chan, *Chest* 2004)

Communication With Stroke Patients – When?

- Initiating medical treatment
- 3-4 months into any treatment
- When medical condition deteriorates
  - Acute medical or surgical crisis
  - Decrease QOL or increase symptom burden
- When patient initiates
- When any member of the multidisciplinary team feels they wouldn't be surprised if the patient died within a year

- ***Talking early allows patients to make own decisions***

Family Discussions about End-of-Life in Stroke

- Concerns of family:
  - Provision of information
  - Management of pain and symptoms
  - Provision of nasogastric feeding and IV hydration
- Tube feeding:
  - Relatives less desirous than professionals
  - Professionals worried about hunger and starving

(Addington Hall, *Stroke*, 1995)

Helping Families Who Missed The Death

- Some family members will miss being present at the time of death
- ***Consider discussing the meaningfulness of their connection in thought & spirit vs. physical proximity***

Goal Setting Process

- Providers should **integrate the best available scientific evidence as well as patient values and preference** when making a ***recommendation about continued care.***
- Because **patient preferences change over time, it is important to periodically revisit discussions** to re-affirm or revise goals and treatment preferences as needed.

Stroke System of Care Needs

- Coordinated by an ***interdisciplinary team***.
- Patients, families, and palliative and non-palliative health care providers ***collaborate and communicate*** about care needs.
- Services are available ***concurrently with, or independent of, curative or life-prolonging care.***
- Patient and family hopes for peace and dignity are ***supported throughout the course of illness, during the dying process, and until death.***

Spiritual Needs

- It is reasonable for providers caring for stroke patients and their families to consider asking their patients about **possible spiritual or religious beliefs and offering referral to a spiritual care provider.**

Social Suffering

- To prevent ***caregiver burnout***, education about the nature of the stroke, stroke management, and outcome expectations, including their roles in those processes, is useful. Caregivers should be provided information on supportive resources. **Caregiver training** may be considered.
- Providers should try to **anticipate, recognize, and help manage grief in patients and families with stroke.**
- Providers should develop ***self-care strategies to monitor for symptoms and to manage burnout*** while providing care to patients with serious and life-threatening stroke.

Social issues

- Dependence and disability issues
- Family and social issues
  - worry about the effects of their stroke on others within their support network.
  - 25% feel that they needed more help than their family could provide.

Addressing Requests for Hastened Death

- Providers may consider developing a strategy for evaluating and responding to requests for **hastened death** in patients with stroke, ***including assessment of suicide and searching for remedies of the underlying problem.***

Role of Hospice

- In patients with stroke, referral to hospice should be considered **if survival is expected to be 6 months or less and when the patient's goals are primarily palliative.**

Summary

- Stroke care is dominated by **clinically challenging**, **emotionally intense**, **and ethically complex medical choices.**

- Palliative should be integrated into all stroke systems of care and managed by the primary stroke team.
  It should be viewed ***not as an alternative to offering life-sustaining therapies, but as an important supplement that can enhance care delivery for patients, families, and providers alike.***

Role of Palliative Care Specialists

- Management of **refractory pain, dyspnea, agitation** or other symptoms, particularly near the end of life.
- Management of more complex **depression, anxiety, grief, and existential distress.**
- Requests for **hastened death**.
- Assistance with goals and methods of treatment, particularly pertaining to options for **long-term feeding and methods of ventilation.**
- Assistance with managing the process of **palliative extubation.**
- Assistance with **addressing cases of near futility** and in families who want everything.
- Assistance with **conflict resolution** whether it be within families, between staff and families, and among treatment teams introducing and transitioning to hospice care.

Conclusions

- Stroke patients experience high levels of morbidity.
- More effective *general* palliative care is required for those dying in stroke units.
- Greater education on *general* palliative care and communication about end of life issues is recommended for staff in stroke units.
- Access to *specialist* palliative care is desirable for certain patients

WHEN
STROKE STRIKES
ACT F.A.S.T.

THANK YOU