



Communicating with people with neurological disorders and their caregivers and ethics in the long-term management of people with neurological disorders

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Learning Objectives

At the end of the lecture, with some additional reading students should be able to

1. Describe difficulties that can be encountered when communicating with patients with neurological conditions
2. Describe communication strategies that can be used with patients with neurological patients
3. Explain some of the key communication challenges faced by physicians treating patients with neurological conditions
4. Describe ethical dilemmas commonly encountered in caring for patients with neurological conditions

Barriers to communication with some patients with neurological conditions

- Language and communication difficulties
- Disorders of emotional communication
- Cognitive changes

Essential skills when communicating with patients with neurological disorders

- Patience
- Empathy
- Involvement of family / caregivers
- Involving other health care professional – eg: speech therapists, psychologists

Communication tips

- Allow extra time
- Avoid distractions
- Listen
- Allow patients to communicate, ask questions and express themselves – use pictures, or other visual aids where necessary or seek support of a speech therapist
- Use visual aids when communicating
- eg; (charts, models pictures(
- Stick to one topic at a time
- Check for understanding
- Summarize frequently
- Use short, simple words and sentences
- Simplify and write down your instructions

Communication challenges faced by doctors caring for patients with neurological conditions

- Breaking bad news
- Addressing advanced care planning and end of life decisions
- Adequately addressing caregiver needs

Breaking bad news – communication at the time of diagnosis

- Patients and caregivers often report of not having enough time for questions, not understanding what diagnosis actually means, not knowing where to go for support, and feeling abandoned by their doctor after being given bad news
- Can use SPIKES (**S**etting up the interview, assessing patient's **P**erception, obtaining patient's **I**nvitation, giving **K**nowledge, address **E**motions, **S**trategy and **S**ummary) protocol to break bad news (Baile et al 2000)

Advanced care planning

- Advance care planning (ACP) is very important for people with neurological disease, who may face later cognitive change.
- Health professionals should be knowledgeable about and feel comfortable discussing advance care planning with their patients while the patient is cognitively able.
- Should be able to initiate discussions with patients and caregivers/ families
- Many patients and families have never heard of advanced care planning
- Research shows patients who engage in end-of-life conversations with their doctors report greater satisfaction with their care; having conversations about death and dying with patients lowers the risk of aggressive treatment at the end of life

Advanced care planning (contd)

- Listening to the person and their family's concerns
- Providing information - enables people to make truly informed choices about their future care; but should not overwhelm or be paternalistic; people cope better when provided with information at a rate they can handle mentally and emotionally
- Important to consider person's wishes and preferences
- Provide opportunities to have open and honest conversations - including end of life care discussions - at all stages of the illness
- Discussing life-prolonging treatments
- Should have some awareness of country specific laws regarding matters and keep appropriate signed forms with medical records

Advanced care planning – topics to discuss

- Medical decisions related power of attorney
- Financial power of attorney
- Living will
- Cardiopulmonary resuscitation instructions
- Overall goals of care including understanding important life goals and patient and caregiver fears
- Encourage patients to communicate their preferences and give relevant consent forms to family members

End of life care in neurological disease

- Need for greater openness and discussion of dying and death
- Effective communication essential so that individual and their family can,
 - Understand as much as they wish to know about the disease
 - Be aware of what may happen as the disease progresses
 - Feel empowered to make informed choices over future care.
- Need to empower patients and families to support each other throughout the course of the disease
- Patient's decision may differ from families

Some prompts to initiate ACP & End of Life Decisions



Do you like to know what is happening with your condition?

How have you been coping with things since you found out about your condition?

What you would like to see happen from here?

In the past, has it been helpful to know a bit more about your condition?

Would it be helpful to talk about how this condition may progress from here?

Caregiver Support

- Caregivers of people with neurodegenerative disorders are at risk of chronic illness, impaired sleep, depression, and cardiovascular disease.
- Caregivers can have up to a 60% increased mortality rate compared with age-matched controls that are not caregivers -increase related to both providing care and strain
- Care needs change over time and caregiver strain shown to increase with neurodegenerative disease progression
- Caregiver quality of life associated with patient quality of life
- Distress rates are lower in caregivers with social support

Addressing caregiver need

- Need to adequately assess caregiver needs - should include questions relating to their ability to provide adequate care to the patient and also to self-care
- Areas to address with caregivers
 - Home safety evaluations
 - Information regarding the illness
 - Understanding the role of medications
 - Knowing who to contact and how to handle complications or emergencies including backup plans for caregiver incapacity.
- Refer caregivers for further counselling or other necessary support when required

Class discussion

Potential ethical dilemmas a doctor could face when treating patients with neurological conditions?

Common ethical dilemmas in neurology practice

1. Getting informed consent from patients
2. Withholding or withdrawing life sustaining treatment
3. Organ donation after cardiac death
4. Pain management related issues
5. End of life and euthanasia related issues
6. Ethics of invasive treatments



1. Getting informed consent

Eg: patients with aphasia, dementia or in a coma

Q. Do patients have the mental capacity to make decisions?

- Prerequisites for patients to exercise autonomy: intact mental capacity, voluntariness and being adequately informed of the risks and benefits of the intervention or treatment to be considered.
- Does patient have the capacity to understand and make correct decisions or to even assign a close person who should get information about his/ her health condition?
- May need to discuss peoples' wishes early, while they still have the capacity to do so (eg those who have neurodegenerative diseases)
- Ethical principle of autonomy and laws of surrogacy should be applied for those who are not cognitively intact

Steps to assessing mental capacity

1. Patient understands the information presented, e.g. the treatment or intervention
being considered
2. Patient is able to register, retain, remember and recall the information given
3. Patient is able to weigh the risks and benefits of a having as well as not having the treatment
4. Patient is consistent and able to communicate his decisions to the healthcare team

2. Withholding or withdrawing life sustaining treatment

Eg Some neuromuscular disorders relentlessly progress, finally resulting in respiratory failure, and death. Amyotrophic lateral sclerosis (ALS) and Duchenne's muscular dystrophy (DMD)

- Patients in terminal stages of neuromuscular disorders, should we provide mechanical ventilation or not?
- When to start, withhold or discontinue artificial nutrition and hydration?
- Should we continue to provide high end ICU/specialized care for patients in a persistent vegetative state?
- How to handle Do Not Resuscitate (DNR) orders?

3. Organ donation after cardiac death

- Point at which retrieval should be done ?
- Transplantation of Human Tissue Act of 1987

4. Pain management related issues

- Prescribing opioids for chronic nonmalignant pain (CNP) disorders (eg: headache, neuropathy, “failed back” syndromes, fibromyalgia, and chronic regional pain syndromes) ?
- Patients with neurodegenerative conditions in palliative stage of care, drugs prescribed to alleviate pain and discomfort for patients that transitioned can have negative impact (eg; respiratory depression and further decrease in level of alertness)
- **Principle of double effect** is applicable when prescribing drugs with intended beneficial effect but with unintended, predictable harmful effects

5. End of life and euthanasia related issues

- 'Mentally competent' patients for whom death is imminent wish to die with dignity?
- Withdrawal of life support vs assisted suicide
- Assisted suicide is illegal in Sri Lanka; only legal in certain countries

6. Ethics of invasive treatments

eg invasive experimental procedures such as deep brain stimulation, cell transplantation, and gene therapy

- Not still that relevant in SL

Long-term management of neurological patients: Some tips for ethical and holistic care

1. Regular review of medications; discontinue if causing behavioural dysfunction
2. Careful communication with patient and family
3. Communication and advance care planning
4. Learn about relevant laws and seek advice before making decisions such as withdrawal of life support etc
5. Multi - disciplinary approach to care
6. Providing holistic care considering psychosocial and spiritual aspects