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Review Article

End of life care in neurologically ill patients – An Indian perspective

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ABSTRACT

End of life care is a critical aspect of healthcare that aims to provide comfort, dignity, and support to patients with life-limiting illnesses, including neurologically ill patients. Neurological diseases such as Alzheimer's disease, Parkinson's disease, Amyotrophic lateral sclerosis (ALS), and brain tumors can profoundly impact a patient's quality of life and pose unique challenges in end-of-life decision-making and care provision. This article explores the importance of end of life care in neurologically ill patients and outlines key considerations for healthcare providers, patients, their families and mentions on the training for healthcare professionals available in India.

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1. Introduction

Neurologically ill patients who have life limiting diseases such as advanced dementia and severe traumatic brain injuries have long and variable disease progression in several aspects such as behavioural issues, cognitive impairment, motor dysfunction and communication difficulties[1] to name a few.

Aggressive neurorehabilitation may provide some respite to such debilitated patients but to an extent. Medical treatments can be futile and bear a huge burden on the family socially, financially and emotionally.

These factors at times may cause the attenders to neglect the ailing patient which might lead them to have a painful agonizing death.

2. End of Life Care

End-of-life care (EOLC) is defined as care of people whose death is imminent (expected within a few hours or days) and those with

1. Advanced, progressive, incurable conditions,
2. General frailty and coexisting conditions if they are at risk of dying from a sudden acute crisis in their condition
3. Life threatening acute conditions caused by sudden catastrophic events.[2]

Good death is achieved when it is free from pain and is supported by family and friends and is in the place of our own choice.[3]

The key elements of care for the dying patient includes:

1. Recognising and accepting that the patient is dying
2. Communication with the patient (whenever possible) and always with family regarding the condition of the patient.
3. Full discussion of the care plan with the patient and relative or carer.
4. Holistic management of symptoms common in EOLC eg. pain, respiratory tract secretions, agitation, nausea and vomiting, dyspnea.
5. Nutritional review, including commencement or cessation.

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6. Regular reassessment of the patient.
7. Dignified and respectful care after death.

3. Common Challenges in End-of-Life Care for People with Neurological Conditions

It is to note that many patients with neurological illnesses die from the complications and not the neurological disease per se.

The common challenges specific to neurological illnesses include

1. The long duration of disease process.
2. Potential for sudden death in some neurological illnesses(e.g., motor neuron disease, multiple system atrophy, epilepsy).
3. Lack of predictable course.
4. Complex multidisciplinary care for geriatric patients
5. Neuropsychiatric problems (e g, behavioral and cognitive changes.
6. Rapidly advancing diseases may need palliative care early in the progression.
7. Inability to swallow and poor venous access.

4. Recognizing the Dying Patient

This poses as a challenge when the family members or patients themselves want to know about how much time they have remaining.

Unfortunately, it is nearly impossible to predict how long it takes for the patient to demise.

However, the few signs and symptoms of imminent death, which can help the physician to predict death which can occur in hours to days are:

1. Profound weakness.
2. Decreasing urine output.
3. Cool and clammy peripheries.
4. The pulse getting weaker; blood pressure gradually falls
5. Respiration becomes shallow, slow, and gradually irregular, may vary in depth.
6. Decreased spontaneous verbalization, interacts less with people, and eventually loses consciousness.

If impending death is diagnosed, the following can be prevented from happening:

1. Further invasive and inappropriate interventions and investigations.
2. Counselling the family and caregivers and clearly explaining the prognosis and what to expect.
3. Emergency hospital and intensive care unit admissions as some patients may wish to spend the last few hours at home.
4. Failure to address symptoms leading to continual distress.

Difficult bereavement. Bereavement support should begin with identifying high-risk individuals before the death of the patient.[3]

5. Symptoms in EOLC, Assessment, and Management

The commonest distressing symptoms are pain, breathlessness, death rattle, agitation, and nausea and vomiting.[4,5]

Other common problems include constipation, oral problems, sleep disturbances, and development of pressure sores.

Physical assessment would include examination of:

5.1. Pain

In neuropalliative care, addressing pain is a vital aspect of improving the patient's overall well-being. A thorough physical assessment, combined with a patient-centered approach, can help manage pain effectively and enhance the patient's quality of life.

History: Obtaining a detailed history from the patient or caregiver is crucial. In many instances, major issues causing intractable pain which go undetected come into light and help save the patient.

Pain Scales: Use standardized pain assessment scales such as the Numerical Rating Scale (NRS), Visual Analog Scale (VAS), or Wong-Baker FACES Pain Rating Scale to quantify pain intensity. Ask the patient wherever possible to rate their pain on these scales to provide a baseline for pain assessment and treatment monitoring.

Pain characteristics: Neuropathic pain, which is common in neurological conditions, may be described as burning, shooting, electric shock-like, or stabbing. Differentiating between neuropathic and nociceptive pain is important for selecting appropriate treatments.

Pain location: Determine the exact location of pain. Patients may experience pain in specific areas related to their neurological condition, such as in the limbs for peripheral neuropathy or along the spine for radiculopathy.

Medication review: Review the patient's current medication regimen, including any pain medications, to assess for effectiveness and potential side effects or drug interactions.

Functional Assessment: Assess the impact of pain on the patient's daily functioning, including activities of daily living, sleep, mood, and overall quality of life.

5.2. Pressure sores

Assessment and management of pressure sores (also known as pressure ulcers or bedsores) are critical aspects of neuropalliative care, especially for individuals with neurological conditions who may be at an increased risk of developing these sores due to limited mobility.

Risk Assessment: Begin by assessing the patient's risk for developing pressure sores. Use standardized tools like the Braden Scale or Norton Scale to evaluate factors such as mobility, sensory perception, skin moisture, and overall medical condition.

Skin Inspection: Regularly inspect the patient's skin, especially over bony prominences (e.g., sacrum, heels, elbows). Look for signs of pressure damage, such as redness, discoloration, or broken skin. Early identification is crucial for prevention.

Staging: If a pressure sore is present, determine its stage using the staging system established by the National Pressure Ulcer Advisory Panel (NPUAP). Stages range from Stage 1 (superficial) to Stage 4 (full-thickness tissue loss with exposed bone, tendon, or muscle).

Wound Bed Assessment: Evaluate the wound bed for characteristics like necrotic tissue, granulation tissue, or infection. Consider using wound assessment tools such as the PUSH Tool (Pressure Ulcer Scale for Healing) to measure wound progress.

Infection Assessment: Assess for signs of infection, including redness, warmth, swelling, increased pain, or foul odour. If infection is suspected, collect appropriate wound cultures for targeted antibiotic therapy.

5.2.1. Management

Prevention: Prevention is the primary goal. Implement strategies to reduce pressure on vulnerable areas, including frequent position changes, the use of pressure-relieving devices (e.g., special mattresses or cushions), and maintaining good skin hygiene.

Wound Care: Depending on the stage of the pressure sore, wound care may include cleansing, debridement (removing dead tissue), and dressing changes.

Offloading: Ensuring that the patient's body weight is adequately redistributed to relieve pressure on affected areas can help minimize risk of development of pressure sores. This may involve using specialized cushions, mattresses, or repositioning techniques.

Infection Control: Management of infections aggressively with appropriate antibiotics, wound care, and systemic interventions if needed.

Nutrition and Hydration – Good nourishment and hydration are vital in wound healing.

Patient and Caregiver Education: Educating both the patient and caregivers on pressure sore prevention, signs of worsening, and proper wound care techniques.

Regular Monitoring: Continuously assess the progress of pressure sore healing and make adjustments to the management plan as needed.

5.3. Bowel and bladder disturbances

Bowel and bladder disturbances are common issues in neuropalliative care, particularly for individuals with neurological conditions. These disturbances can significantly impact a patient's quality of life and require careful assessment and management. Here's a guide on how to assess and manage bowel and bladder disturbances in neuropalliative care:

5.3.1. Assessment

Bowel Assessment- Evaluate bowel function, including frequency of bowel movements, stool consistency, and the presence of fecal incontinence or constipation. Use tools like the Bristol Stool Form Scale to classify stool consistency.

Bladder assessment - Assess bladder function, including urinary frequency, urgency, incontinence, and difficulty emptying the bladder. Consider using bladder diaries to track voiding patterns.

Diagnostic studies - Depending on the patient's presentation, consider diagnostic tests such as urodynamic studies, cystoscopy, or imaging (e.g., MRI) to evaluate the urinary tract and rule out structural abnormalities or obstructions.

5.3.2. Management

Patient Education - Educate the patient and their caregivers about the nature of the bowel and bladder disturbances, potential causes, and available management options.

Medications- Depending on specific symptoms, medications may be prescribed.

Bladder training - Implement bladder training techniques to help patients regain control over their bladder function. This includes scheduled voiding and pelvic floor exercises.

Catheterization - In cases of urinary retention or incontinence, intermittent catheterization or indwelling catheters may be necessary. Proper catheter care and hygiene are essential to prevent complications.

Bowel management - For severe bowel disturbances, a bowel management program may be established, which can include dietary modifications, the use of suppositories or enemas, and digital stimulation.

Physical therapy - Engage physical therapists to provide pelvic floor rehabilitation and exercises that can improve bladder and bowel control.

Nutrition and hydration - Ensure the patient maintains adequate hydration and a balanced diet to promote regular bowel movements and urinary health.

Psychosocial support - Offer psychological and emotional support to patients dealing with the challenges of bowel and bladder disturbances. Counseling or support groups may be beneficial.

Continence supports - Provide access to continence products like adult diapers, pads, or catheter supplies to help manage incontinence and maintain dignity.

Advanced Interventions - In some cases, surgical interventions may be considered, such as urinary diversion surgery or bowel resection, depending on the underlying cause and the patient's overall health and preferences.

In neuropalliative care, the management of bowel and bladder disturbances should be individualized, considering the underlying neurological condition, the patient's goals of care, and their overall comfort and quality of life. A multidisciplinary approach involving neurologists, urologists, physical therapists, and palliative care specialists is often necessary to provide comprehensive care and improve the patient's well-being.

Psychological assessment of beliefs, fears, and anxieties can help physicians to help patients and their families.

Spiritual distress may be relieved by talking with a person with whom the patient feels comfortable. Some patients can have overwhelming distress often related to unresolved conflict, guilt, fears, and feeling of loss of control.

Management of distressing symptoms includes pharmacological measures.

Alternate routes like subcutaneous and rectal routes work well in EOLC.

If patients are with NG feeds, this route can also be used.[3]

6. Management of Other Common Symptoms

1. Breathlessness with anxiety can be treated with benzodiazepenes
2. Respiratory secretions that can cause "death rattle" can be controlled with suctions and anticholinergics[6]
3. Nausea and vomiting can be addressed with antiemetics
4. Terminal restlessness can be controlled with haloperidol and benzodiazepines. These medications can be given either as a bolus dose or as an infusion.

Communication at each stage of management is vital is important and addressing the queries of attenders can help alleviate anxiety in them and develop confidence in the physician.[7]

7. End of Life Care in India

EOLC in India, like in many other countries, is a critical aspect of healthcare aimed at providing comfort, support, and dignity to individuals nearing the end of their lives.

Previously published studies in palliative care journals were on reporting of moral problems,(ethical issues),[8] euthanasia,[9] and religion and spirituality.[10]

Legal Framework: India does not have specific legislation addressing end-of-life decisions like euthanasia or physician-assisted suicide. The issue remains a subject of ethical and legal debate. The Supreme Court of India has issued guidelines on "passive euthanasia" in certain cases, allowing the withdrawal of life support under specific circumstances with proper legal safeguards.

Hospice Care: Hospice care is a specialized form of end-of-life care that provides comprehensive support to individuals with terminal illnesses. There are various hospice facilities and home-based hospice care services available in India. These facilities aim to provide comfort and support in a homely environment.

Family-Centric Approach: In India, family plays a central role in end-of-life care decisions. Families often make decisions collectively, taking into account cultural and religious beliefs. This can sometimes lead to complex decision-making processes, and healthcare providers must respect and involve the family in care decisions.

Cultural and Religious Diversity: India is a diverse country with various cultures and religions. This diversity influences end-of-life care practices and beliefs. Healthcare providers must be sensitive to the cultural and religious preferences of patients and their families when providing care.[11]

Home-Based Care: Many individuals in India prefer to receive end-of-life care at home, surrounded by their loved ones. Home-based care services and palliative care teams can provide medical and emotional support to patients and families in their homes.

8. Training in Palliation and End of Life Care

According to the 2015 Quality of Death Index report, the palliative care provision in India is poor due to a low-demand and low-supply situation.[12] However, training in palliative care and need for end-of-life care in India has increased as the country's healthcare system continues to evolve. Here are some key aspects of training in palliative and end-of-life care in India:

Postgraduate Courses: After completing undergraduation, healthcare professionals interested in palliative care can pursue postgraduate courses, such as MD programs, or fellowships in palliative medicine. These programs provide in-depth training in the principles and practice of palliative care.[13] All India Institute of Medical Sciences (New Delhi), Cancer Institute Adyar (Chennai), Tata Memorial Hospital (Mumbai), Gujarat Cancer and Research Institute (Ahmedabad), Sawai Man Singh Medical College (Jaipur), Amrita Institute of Medical Sciences (Kochi), Kasturba Medical College, Aster CMI, St. Johns National Academy of Health Sciences (Bangalore), MNJ Institute of Oncology (Hyderabad) are a examples of institutes running full fledged postgraduate courses in palliative care.

Workshops: Various hospitals and organizations across India offer workshops and training programs in palliative care. These programs are typically designed for healthcare professionals, including doctors, nurses, social workers, and psychologists. They cover topics like pain management, symptom control, communication skills, and psychosocial support.

Online courses: With the growth of online education, there are also many e-learning platforms that offer courses in palliative care. These courses can be a convenient option for healthcare professionals looking to enhance their skills in this field.[13] CCEPC by the IAPC (Indian Association of Palliative Care), FCPM by PALLIUM India are conducted virtually where one can learn the basics of palliative care principles.

Conferences: Attending palliative care conferences and seminars is another way to gain knowledge and network with experts in the field. These events often feature presentations on the latest research and best practices in palliative care.

Government Initiatives: Some state governments in India have initiated palliative care programs and training opportunities.[14] For example, Kerala has a well-developed palliative care system, and the government has supported training and education in this area.[15]

It's important to note that while palliative care training is growing in India, there are still challenges in terms of accessibility and awareness. Efforts are being made to integrate palliative care into the mainstream healthcare system and to improve training opportunities for healthcare professionals across the country.

9. Conclusion

End of life care for neurologically ill patients is a complex and sensitive endeavor that requires a holistic approach. It involves open communication, symptom management, palliative care, and respect for patients' values and preferences. Addressing the unique challenges posed by neurological conditions is essential to ensure that patients and their families receive the support, dignity, and comfort they need during this difficult time. By following these principles and remaining committed to the well-being of the patient, healthcare providers can make a meaningful difference in the lives of neurologically ill patients and their Exploring spiritual distress is not easy at all and is characterized by overwhelming distress often related to unresolved conflict, guilt, fears, and/or feeling of loss of control. With the increasing population and advancements in healthcare, we can expect an increase in number of people with neurological diseases which are debilitating and life limiting who may opt for palliative care and trained healthcare personnel in palliative care would be the need of the hour.

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11. Conflict of Interest

None.

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