

## Neuro Palliative Care and its Role in Modern Medicine

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### ABSTRACT

Just as Palliative care is a rapidly growing medical specialty, Neuropalliative care, with a focus on holistic care of the neurologically seriously ill, is emerging as an important subspecialty. It starts with the diagnosis of the disease and continues into supporting the patient and care givers through their journey with the disease. Although amongst the medical fraternity the concept is still hazy and represents care of patients for whom 'nothing more can be done', palliative care is the best of what a compassionate medical care can offer and is the most beautiful aspect of modern medicine. The application of palliative care needs good multidisciplinary teams with the physician in the lead. Neurology being a field of complex diagnoses and several illnesses with limited curative treatment, Palliative care with a team approach is an essential adjuvant to overall management.

**Key words :** Neuropalliative care, Hospice service, End-of-Life-Care.

### Introduction :

The word 'palliation' is automatically associated with cancer. Even in the minds of doctors, it is associated with a medical state where 'nothing more can be done' hence the patient may be sent for 'palliative care'. It is unfortunately equated with 'giving up' on the patient. People, doctors included, confuse between Hospice services and palliation.

In the field of Neurology, like all the other fields of medicine, a lot of progress has been made and some fields of neurology are now equivalent to the active interventional heroism of cardiology and critical care. We are saving lives and reducing morbidity in acute stroke and other critical neurological emergencies. However on the other extreme, the indolent chronic neurodegenerative diseases continue to disappoint the curatively obsessed physician inside us. But the fact is that the patients of these diseases exist and will continue to rise as people live longer due to improvements in lifestyle factors and better medical care for several other diseases. It is time we question : Is curative treatment the only approach to enthusiastic medical care? If compassion and empathy are the basis of medical care, then what should be the approach to

management of chronic diseases? For diseases, which have no curative treatment, what should be the goal of management? The answer to all these questions lies in Neuro-palliative care, which is emerging as an important subspecialty.<sup>1</sup> Efforts are being made to establish it in India by providing training and mentorship.<sup>2</sup>

### Terms in Palliative Care :

1) **Palliative care** : The Centre to Advance Palliative Care (CAPC) defines Palliative Care as 'Specialized medical care for people with serious illnesses. This type of care is focused on providing patients relief from symptoms, pain and stress of a serious illness, whatever the diagnosis. The goal is to improve quality of life for both the patient and the family. Palliative care is provided by a team of doctors, nurses and other specialists who work with a patient's other doctors to provide an extra layer of support. Palliative care is appropriate at any age and at any stage in a serious illness and can be provided together with curative treatment'.<sup>3</sup>

Accepting and planning for decline and eventual death as an expected outcome of the illness, is an inherent part of Palliative care.<sup>1</sup>

2) **Hospice** : hospice care is a type of care (and philosophy of care) that focuses on the palliation of a chronically ill, terminally ill or seriously ill patient's pain and symptoms and attending to their emotional and spiritual needs. Hospice

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staffs have skills and experience to facilitate care transitions for seriously ill hospitalized patients.<sup>4</sup> Since it is an inpatient facility, with nursing and other staff attending and taking care of most needs, Hospice care refers specifically to palliative care for the end of life.

- 3) **End-of-life care** : (EOLC) This is related to the care that is to be taken of the terminally ill patient. The death trajectories of different diseases differ to a large extent. The common trajectories are as follows : 5

Trajectory 1 : short period of evident decline, typically cancer, Motor Neuron Disease

Trajectory 2 : long term limitations with intermittent serious episodes : Heart failure, Chronic Obstructive Pulmonary Disease, Relapsing Remitting Multiple Sclerosis.

Trajectory 3: prolonged dwindling : Neurodegenerative diseases.

The trajectories are important. They teach us that “doing everything that can be done for a possible cure” may be misdirected.

- 4) **Advance care planning / Advance Directives** : This refers to a process of considering, discussing, planning and communicating one's health-care treatment goals in the framework of one's values. These are then codified in a document termed the ‘living will’ or ‘advance directive’ (AD) which becomes operative if and when the patient is unable to communicate. EOLC discussions can be held under AD. Non-medical wishes such as spiritual care may also be addressed. The AD also includes the appointment of a surrogate (medical power-of-attorney) to make decisions in case discretionary judgment is required in a given situation of end of life.<sup>6</sup>

### **Role of palliative care in modern Neuro-medicine : A team approach**

In a 1996 review, the American Academy of Neurology Ethics and Humanities Subcommittee stated : “Many patients with neurologic disease die after long illnesses during which a neurologist acts as the principal or consulting physician. Therefore,

it is imperative that neurologists understand, and learn to apply, the principles of palliative medicine.”<sup>7</sup> The approach to managing a patient with palliative care as a tool can augment care for neurology patients.<sup>1</sup> The traditional modern medicine teachings stress on preservation of function and prolongation of life. However, palliative care focuses on relief of suffering and improving quality of life (QOL) during the forthcoming period. It stresses the importance of accepting the diagnosis, understanding the prognosis, and planning for decline and death as an expected and natural outcome rather than as a failure of medical treatment.<sup>1</sup>

Palliative care also involves the care-givers and gives them a platform to express their strains and concerns and offers them support to overcome them. Medical management, respite care, psychosocial support including counseling, accepting diagnosis, understanding prognosis, support in activities of daily living (ADL), planning for end of life and advanced directives, hospice care and addressing spiritual issues are all a part of the spectrum of palliative care. Hence it is an effort by a team of caring and empathetic people : physician, nurse, social worker, and volunteers. Palliative care teams should, thus, be trained and experienced not only in complex symptom management, but more importantly also in challenging communication interactions, including medical decision making and aligning goals of immediate and distant care. This is the way forward to bridge the doctor and society communication gap and to re-establish the trust and faith.

### **Need for palliation in Neurology :**

The field of Neurology has gone through several transitions. In earlier days it was a field of analytical reasoning processes, which led to complex diagnoses, and the actual management was left to other physicians. With the advance in radiology, other diagnostic procedures and therapeutics, there was a change in approach in Neurology as diagnostic methods went beyond mental skills. Protocols were developed for managing various diseases and disorders. A further new era of neurocritical care emerged with thrombolysis for

**Table 1 : Top Ten things Palliative care clinicians wished everyone knew about palliative care<sup>8</sup>**

	What palliative care clinicians want others to know
1	Palliative Care can help address the multifaceted aspects of care for patients facing a serious illness
2	Palliative care is appropriate at any stage of serious illness
3	Early Integrative palliative care is becoming the new standard of care for patients with advanced cancer
4	Moving beyond cancer: palliative care can be beneficial for many chronic diseases
5	Palliative care teams manage total pain
6	Patients with a serious illness have many symptoms that palliative care teams can help address
7	Palliative care can help address the emotional impact of a serious illness on patients and their families
8	Palliative care teams assist in complex communication interactions
9	Addressing the barriers to palliative care involvement : Patients' hopes and values equate to more than a cure
10	Palliative care enhances health care value

acute ischemic stroke and plasmapheresis and IVIG for autoimmune storms. However, there still remain a number of illnesses that defy all advances in curative treatment and progress into terminal stages. Some neurological diseases are incurable and reduce the life expectancy.<sup>9</sup> Moreover they are associated with symptoms of pain, depression, behavior problems and other symptoms that are difficult to control<sup>10</sup> and interfere with smooth ADL. It has been shown by Miyasaki et al<sup>11</sup> that symptom burden in advanced Parkinson's disease is similar to that in metastatic cancer. Care-givers of Neurology patients also go through burnout, distress and depression as those of patients with cancer.<sup>12</sup>

'Cure' cannot be an end point of management of these diseases and disorders. The other 'C's are equally essential. Control - of symptoms, Coping - with the diagnosis, disability and dependency, Comfort - from symptoms that interfere with a good quality of life and ADL. Palliative care provides these three Cs and complements other treatment for these patients.

And yet it is not just for the terminal diseases that palliation is important. Palliative care, in principle, is an adjuvant to treatment for most diseases. Symptoms in most Neurological illnesses, (even those that revert to normalcy after weeks and months, e.g. GBS) are such that they affect the ADL of an individual, either temporarily or progressively. They result in dependency of the patient on the care-giver for that period of time, acting as limitations for the care-giver too. The treating team can provide

control and comfort from distressing symptoms, improve QOL and provide holistic care.

Fundamental skills needed for Neuro-palliative Care in everyday practice : 1

1. Communication at the time of diagnosis and at crucial turning points of decision making related to treatment
2. Non-Motor symptom assessment and management
3. Advance care planning
4. Care-giver assessment

For more complex problems, the patient can be referred to a specialised palliative care facility.

#### **Communication skills and breaking bad news :**

Communication skills of the palliative care team form the foundation of good care. It is essential to understand what the patient and the care givers have understood, giving them time to assimilate the information, making them comfortable to express their concerns, following up with them to know their expectations from the care program and discussing goals of care. The current medical curriculum does not include training for these skills. The palliative care physician and the entire team should be trained in the different ways in which interviews and discussion meetings for serious illnesses can be conducted. Various protocols have been developed as shown in *table 2*. Training for these skills is imparted through interactive workshops with simulations and role plays. The principles of good

communications should be applied in day to day practice.

#### Symptom management

**Unique needs of Neurology patients :**<sup>1</sup> The patients with general medical conditions or cancer have needs which have been studied, protocols made and methods developed to deal with them through palliative measures. However, these protocols and methods cannot be blindly applied to neurological patients, as their needs and those of their care-givers are unique. The trajectory of progression of neurological diseases is variable.

Patients with Parkinson's disease,<sup>11</sup> MS, and MND can be significantly afflicted by non-motor symptoms of varying complexities - such as sensory symptoms, including neurogenic pain, continence issues, depression, anxiety, fatigue, sleep disorders,

sexual dysfunction, behavior problems, cognitive impairment, psychotic features, loss of identity and so on<sup>10</sup>. Through the course of a long illness, these probably affect the QOL more than the motor disability. Cognitively impaired patients can develop behavioral and psychiatric symptoms that increase caregiver burden several fold. Managing these QOL symptoms forms the crux of Neuro-palliative care.

While the cancer patient perceives the 'cancer' as something 'outside' of themselves, the neurology patient perceives the disease as 'intrinsic' to themselves at a spiritual level.<sup>1</sup> The disabilities being physical and also cognitive, a feeling of being a 'burden' to the family can take strong emotional hold and lead to further depression, demoralization and even suicidal ideation<sup>16</sup>. A few neurological illnesses such as Motor Neuron Disease<sup>16</sup>,

**Table 2 : Breaking bad news : suggested plan, incorporating elements of SPIKES, BREAKS and NURSE<sup>2,13,14,1</sup>**

	Purpose	Act
1.	Getting the setting right	Know the clinical problem (prognosis, treatment, etc.)
		Know the context (family, social, economic, etc.)
		Ensure privacy, time. Sit at the same level
		Make eye contact, keep body language congruent
2.	What does the patient/ family know already?	'What have you been told?'
		'What do you understand?'
		Note vocabulary, comprehension, denial
3.	Does the patient/ care giver want to know?	Check willingness with explicit questions
		If declined, leave option for future
4.	Give information	Align: keep to recipients' level of comprehension
		Educate: preferably not more than 3 pieces of information
5.	Dealing with emotions and reactions (NURSE)(15)	Name and Understand the emotion
		Respect and Support the emotion
		Explore the emotion
		Deal with strong reactions: crying, anger, etc.
6.	Closing	Summarize
		Express personal support
		Check for safety, suicidal ideation
		Fix plans for the next meeting

*SPIKES : 13 Setting up the interview, Perception (patient's) assessment, Invitation (patient's) acceptance, Knowledge imparting, Emotions addressed, Strategy and Summary*

*BREAKS : 14 Background, Rapport, Explore, Announce, Kindling, Summarize.*

*NURSE : 15 Name, Understand, Respect, Support and Explore emotions*

Dementia<sup>17</sup>, Huntington's Disease<sup>18</sup>, Multiple Sclerosis<sup>19</sup>, have been studied for evaluating these aspects. The dying trajectory for such terminal neurologic illnesses differs from that of cancer.

Thus, symptom profiles, psychosocial problems, needs of caregivers, spiritual issues, surrogate decision-making and variable trajectory are some of the unique features of neurologic diseases. Hence the palliative physician trained in internal medicine may have less comfort and expertise with neurologic illness as compared to cancer or other medical diagnoses.<sup>20</sup>

### **Role of advance care planning in Neurology**

The neurologist is sometimes called upon to opine on the decision-making capacity (DMC) for the standard legal wills. As dementia and other neurodegenerative diseases progress, the patient's cognition gets affected and patient reaches a stage where decision-making is not possible. Hence the Neurologist should be comfortable in discussing advance care planning with patients while they are cognitively able.<sup>1</sup> It is the assumption of Cure-obsessed perspectives that patients would not be comfortable talking about death and dying. However, patients expect the physician to initiate these conversations.

As life nears the end, compassion may be misplaced and might lead to unnecessarily aggressive decisions for interventions that only postpone death but prolong agony at the expense of stripping the dignity away from the suffering patient. It is essential to understand the futility of medical interventions when the disease has reached an irreversible stage. Patients who engage in end-of-life conversations with their doctors report greater satisfaction with care. In addition, such conversations lower the risk of aggressive treatment at the end of life.<sup>1</sup>

Worldwide surveys, asking where would a person like to die, have revealed that people, if given a choice, would like to die at home, amongst family members.<sup>21</sup> Considering this, creating an environment at home, with comfort for the patient at the time of exit, is also a matter of intelligent and sensitive planning.

Advance care planning<sup>22</sup> includes discussion about AD, power of attorney, cardiopulmonary resuscitation directive. Advance Directives (AD) are legally valid and enforceable in most western democracies but not yet in India. A team of Indian doctors (ELICIT) is working towards the legalization of enforcement of ADs. However, a written document with explicitly expressed wishes in presence of witnesses does have value. The format of Five Wishes can be followed for noting down ones wishes for AD.<sup>23</sup>

### **Caregiver assessment**

Caregivers are at risk of chronic illness, impaired sleep, depression, and cardiovascular disease, and can have up to a 60% increased mortality rate compared with age-matched controls that are not caregivers.<sup>1</sup> Caregiver QOL is also associated with patient QOL - These negative feelings of depression and demoralization that the patient has are often passed on to the care-giver, leading to a decline in their QOL.<sup>17</sup> Their process of bereavement is also complex and goes through stages different from that of a cancer death.<sup>24</sup> Thus, when patients spend their last months of life in the intensive care unit or die a traumatic death, it affects caregivers. The following are example questions neurologists can use to assess caregiver well-being<sup>1</sup> : Are you feeling overwhelmed? How is your health? What are you doing to take care of yourself? Do you feel isolated? Do you have time to meet your financial, work, parental, or other obligations? With these simple questions, neurologists can provide caregivers with important validation and may be able to address issues directly or refer caregivers for further counselling or other necessary support (e.g., respite or home health services).

### **Conclusion :**

With the changing scenario of practice in Neurology, there is a definite need to extend palliative care to this field. Training of practicing Neurophysicians and building of multidisciplinary teams is the way forward towards holistic care of untreatable chronic illnesses. Palliative care can be considered to be a spectrum of patient and care-giver directed services, which starts with appropriate

symptom relief in its simplest forms and goes to hospice care and end-of-life care management in its entirety. An additional factor in Neurology becomes the management of cognitive symptoms and end-of-life decision making especially during times when patient suffers from loss of identity due to the illness.

The social structure, especially in the cities, is changing. The traditional family support is seen dwindling and nuclear families, single adults are on the rise. We may bring robots and automation into medical practice, but there can be no substitute for empathy and compassion. This is the foundation of palliative care. Palliative Care principles offer routes to holistic management of an illness with focus on QOL, rather than duration, including care of Caregivers. The care givers are an important part of the triad of the palliative care team. They are the innocent bystanders who also bear the brunt of the Neurological illness, with a chance of facing complicated grief after the patient's death. And addressing this aspect is important. A good death is, after all, remembered more positively than a traumatic experience with an efficient ICU team!

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