

Editorial

Neuropalliative Care for India: Who, What, When, Where, Why, How?

Palliative care (PC) is an intersectional specialty, akin to intensive care, born in the 1960s.¹ Beginning in the UK it soon spread across the world. In 2014 the World Health Assembly formally recognized the importance of PC and in 2017, the World Bank's Disease Control Priorities defined a model concept of essential universal health coverage (UHC) with PC included as an ethical service responsibility. It was part of an essential services package designed to be affordable everywhere, with a focus on relieving suffering and limiting catastrophic health expenditures. When it began, PC's focus was on cancer pain. Dame Cicely Saunders, who is considered the founder of the modern hospice movement, soon realized that total pain: physical, psychosocial and spiritual, needed to be addressed together. Learnings from the social sciences were incorporated. But it was in the USA in the 1970s to 1990s that human-patient-consumer rights all came together. Patient autonomy, rights at the end of life and the relief of suffering all became part of mainstream medicine. In the early 2000s, neurologists, mainly in the USA, began to realize that our patients needed these services as much as cancer patients and perhaps more.²⁻⁴ By mid-2021, the proponents coalesced into the International Neuropalliative Care Society (INPCS).⁵ Globally, neurological illnesses are the leading cause of disability and the second largest cause of death. In India, stroke was the leading cause of death in Gadchiroli in rural Maharashtra.⁶ How do our numbers compare against oncology? In Mallapuram in Kerala,⁷ where PC need is community-driven, enrolments for dementia (19%) and stroke (17%) have already outstripped cancer (32%).

But palliative care in neurological patients has specific challenges.⁸ The first is the threat to personhood: loss of autonomy, cognition and overall function. Joy, meaning and purpose are key to quality of life, and all of these are hit. The timelines of neurological disease often stretch into decades. There is major variability in disease progression between patients with the same disease. This leads to uncertainty not only about prognosis and trajectories, but also about support availability and planning. Think of a childless elderly couple when one of them develops dementia. Impairments in cognition and speech are an intrinsic part of many neurological illnesses and as a result our interlocutors are not the patients themselves but their families and caregivers. But these are not the only barriers. Physicians, caregivers and families all vary in their approach to information (seeking, giving and receiving), attitudes to care and skill sets, and this inconsistency is another major issue. Think of a person with Parkinsonism whose main care partner, the spouse passes away and who is now being taken care of by one of the children. Location and physician changes are accompanied by cognitive decline. Since no one knows what the patient wanted, the last stage is on life support in an intensive care unit (ICU). All of this leads to substantial existential and spiritual distress for the patient and family. A true-life account shows how different this can be for cancer, where the patient retains control if she desires, almost till the very end.⁹

To address these challenges, in addition to standard neurological management, needs have to be addressed under the following domains of care:¹⁰

1. *Structure and process of care:* Most care is provided at home and the care provider may be a family member or a paid caretaker. Kerala has, in addition, a network of trained volunteers who handle much of home PC. This kind of training can be augmented to provide a semi-skilled combined workforce for dementia, geriatric and palliative care under the National Skill Development initiative.

2. *Physical symptoms*: Management focuses on functional status and quality of life. Validated tools are available, which can be filled out easily by the patient/caregiver and allow the provider to concentrate on the most pressing symptomatic needs.
3. *Psychological care* is based on regular screening of patients for depression, anxiety, demoralization and delirium. But caregivers and providers also need monitoring for burnout. These issues need counsellors rather than psychiatrists.
4. *Social aspects*: Isolation and stigma are common but our assessment also has to incorporate resilience, coping strength of the family, support from relatives and access to food, housing and transportation.
5. *Spiritual issues*: These are distinct from religion and refer to the need for meaning and purpose in life. These allow the individual to connect with those around them and are expressed in rites, beliefs and values. The idea of 'sewa' (service), to give and to receive, makes the disease journey meaningful. In the USA, secular chaplains provide these services. Till we have this specialty, the clinician and psychologist have to be sensitive to this need. Often all it takes is a simple one question screen: 'Are you at peace?' ('*Kya aap ka man shant hai?*').
6. *Cultural aspects*: These include the acceptance of diversity with humility. Social class, ethnicity (caste/race) and sexual identity are all distinct from religion and we need to be aware when the biological family is not the family of choice.
7. *Terminal care*: Unlike cancer, the transition from basic PC to end-of-life care is difficult to identify in neurology. Active dying in oncology and most non-oncological PC is marked by psychosocial withdrawal weeks-to-months before death. In our patients, this can be stretched for years. And yet families are unprepared for the inevitable. Management at this stage has to be preference-based in addition to incorporating evidence-based symptomatic management.
8. *Ethical and legal aspects*: It has been stated that ethics asks the question and points out the route but the law has to provide the solution. In India today, the situation is evolving. The Supreme Court has confirmed the validity of the right to death with dignity but only legislatures and Parliament can make this happen. Professional guidelines are already available and the ethical practitioner is more than adequately protected if she follows them.

All of the above challenges and needs come together in a perfect storm with serious acute brain injury.¹¹ This specifically refers to patients admitted in coma (GCS \leq 8, lasting >6 hours), with conditions such as trauma, stroke and anoxic brain injury. Not many realize that with the best neurocritical care, the chances of recovery to normalcy are in the range of 10%–20%. Intensive care and PC must work together when difficult decisions have to be made.¹²

The macro problem of PC in India is both of low demand and low supply. India as a polity is unlikely to ever have UHC and the experience of the USA is instructive.¹³ Adequate PC is not possible without UHC. (The interested reader is referred to an earlier policy article in this *Journal*.¹⁴) But we do have low hanging fruit in neuropalliative care. Two areas that call for immediate attention are:

1. *Communication skills*: These are learned skills with proven protocols,¹⁵ which are meant for everyone in medicine, not just neurology. At the beginning, when bad news must be delivered, we often fail to realize that what seems to us a simple diagnosis of epilepsy in a child, may be a bombshell for the mother. As disease progresses, we forecast possible futures and foretell with compassion. Goals of care can then be discussed.
2. *Making neurological knowledge accessible*: Our numbers are too large for neurologists to manage. We must commit to teaching, but with humility, everyone around us, including lay persons. From its inception, the INPCS is multidisciplinary, with a strong focus on education.^{16,17}

In oncology at a certain stage, the patient can be handed over to palliative and end-of-life care. Neurology does not offer such an easy option. I explain this with the visual metaphor of a map (Fig. 1), tracking the journey of a patient with a life-limiting neurological illness. Neuropalliative care may seem a complex, time-consuming process but that is a short-sighted view. Neurologists have among the highest rates of burnout among physicians. Over the past few decades, the specialty has seen huge strides in diagnostic capabilities and also in the therapies that we can offer. But that is not enough. If we understand that making a diagnosis is just the beginning of a long

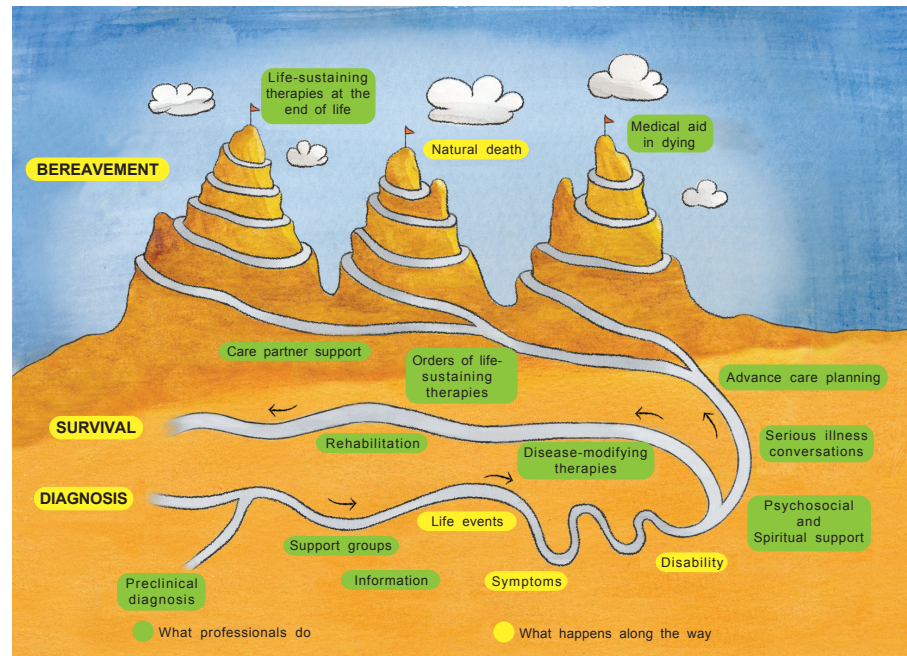


FIG 1. The roadmap model of neuropalliative care. (Prepared for this article by the author with Makarand Dambhare [artist])

journey, we accept the privilege of walking with a fellow human along a part or all of it. Speaking as a practising neurologist, once the skills of prognostication and communication are acquired, they slip seamlessly into daily practice and the meaning and purpose of being a physician come alive.

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