

## What is Neuropalliative Care: Making it Work in India

### ABSTRACT

The burden of neurologic disease is substantial and rising worldwide. India is no exception. These illnesses cause prolonged disability and distress for the patient, family, and community. Palliative care (PC) is an approach that focuses on providing relief from suffering. Till about two decades ago, PC was largely restricted to oncology but there is now a growing community of health-care providers and others, working to incorporate the same principles in the care of our patients, through the International Neuropalliative Care Society. This paper outlines the evolution of this new subspecialty and the knowledge and skill sets required to practice it. Education and research priorities are important and are also discussed.

**Key words:** Palliative care; Neuropalliative; Severe acute brain injury; Long term neurologic conditions; Quality of life; Dementia

### INTRODUCTION

Neurologic disorders are the leading cause of disability and the second largest cause of death worldwide, as estimated by the Global Burden of Disease project.<sup>[1]</sup> This burden is projected to continue to rise as life expectancy increases and the epidemiologic shift away from infectious disease progresses. Long-term neurologic conditions (LTNCs) are incurable and often lead to dependence long before death, so that their consequences in terms of suffering are borne by the family and the wider community. Care for these individuals has to encompass the family as well and must strive to improve the overall quality of life (QoL) by addressing physical, psychosocial, and spiritual suffering. In the acute setting, catastrophic brain injuries (CBI) requiring neurointensive care, raise complex issues of ethics and law when permanent and severe disability appears inevitable. Navigating decision-making in these situations requires communication skills of a high order. Till the middle of the last century, medicine did not have a coherent solution to these issues. It was only in the 1970s and later that palliative care (PC) developed as an intersectional specialty, working with and across other medical specialties for the care of seriously ill and dying patients. In the past two decades, it has grown spectacularly across developed countries. For instance, almost all large hospitals in the USA now have PC services to which neurology patients have full access. In contrast, in India, PC teams and hospice beds are generally available only for cancer. The way out was recognized more than 20 years ago. The following statement from the American Academy of Neurology Ethics and Humanities Subcommittee is dated to 1996.<sup>[2]</sup> “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.” As physicians, we have always prioritized

Roop Gursahani<sup>1</sup>, Prafulla Shembalkar<sup>2</sup>

<sup>1</sup>Consultant Neurologist and Epileptologist, P. D. Hinduja National Hospital, Mumbai, Maharashtra, India, <sup>2</sup>Neurologist and Director, Getwell Hospital and Research Institute, Nagpur, Maharashtra, India

#### Corresponding Author:

Roop Gursahani, Consultant Neurologist and Epileptologist, P. D. Hinduja National Hospital, Mumbai, Maharashtra, India. Phone: +91-22-24447201/ Cell: +91-9821087597. E-mail: roop\_gursahani@hotmail.com

management focused on cure. Since this is often not possible in LTNCs, our aim has been maintenance of functional ability together with life prolongation. PC helps further shift our focus to care, accepting decline and death as a natural outcome and allowing us to maximize relief of suffering.

### HISTORICAL BACKGROUND

#### Origins of PC

Although hospices as places for the dying have been around since millennia, they have always been thought of as a charitable religious activity. PC as a modern specialty really began in the United Kingdom in the grim, economically deprived years after the World War II. The UK's universal health-care (UHC) organization and the National Health System had just been set up. However, the origins of PC are the story of one remarkable woman. Cicely Saunders<sup>[3]</sup> (1918–2005) began as a wartime nurse, then trained as a social worker and finally qualified as a medical doctor. Along the way, voluntary work with terminally ill cancer patients and experience with pain control with morphine was combined with rigorous documentation and research.

There was then, and still is, a great reluctance to use opioids. Working at St Joseph's Hospice, she accumulated records and photographs of over a thousand patients showing how much difference could be made in the last period of life of someone terminally ill with cancer. Lecturing widely and collaborating with other professionals working with pain relief allowed her and others who joined to spread this message across the world. By the 1960s, she had developed the concept of total pain in severely ill individuals.<sup>[4]</sup> This recognizes that physical pain is almost always combined and often overshadowed by social (including economic) woes, psychologic distress and spiritual (or existential) burdens and doubts. Mainly through her drive and determination (someone called her "Hurricane Cicely!") but also her ability to inspire a team, the UK has two institutions that are at the forefront of research, training, and service for PC. The first was St Christopher's Hospice (1967) and finally the Cicely Saunders Institute (2010). Both because of these efforts and because the NHS supports PC as an essential component of universal healthcare, the UK topped the Quality of Dying Index in 2010 and 2015.<sup>[5,6]</sup> Toward the end of her days, she is quoted as having said "If one man from a poor village in India dies without pain because of what I have done, it will all have been worthwhile."

#### The evolution of the zeitgeist, living with dying

Zeitgeist means the spirit of the age we live in. Our concepts of medical ethics evolved as part of a broader elaboration of human rights. Human equality was not a given till well into the 20<sup>th</sup> century. Doctors could and did expect to rule their patients' lives ("medical paternalism"). The horrors of the Nazi concentration camps and especially the medical experiments, led to the Universal Declaration of Human Rights and the Nuremberg code on human experimentation.<sup>[7]</sup> Over the next few decades, this became part of mainstream medicine as therapeutics advanced. Till the discovery of antibiotics and the invention of intensive care, death was the rule in critical illness. It was only after the 1960s that people could expect to recover and that led to the realization that not everyone could be salvaged. We reached a situation where the individual human was often lost between the irreversible truth of biology and the rising force of medical technology. Earlier death was all around us but now it was medicalized and occurred largely away from public gaze in hospitals. The counter thrust began in the 1960s as human rights led to consumer rights and then to patient rights and finally the rights of the dying. This was a time of great political ferment in the USA with the Civil Rights movement for racial equality. The first living will was propounded in California in the late 1960s. In the next two decades, the USA became the world's laboratory for these instruments as state after state enacted laws almost competitively. The rest of the developed world began to catch up. These concepts resonated in India but our medical

jurisprudence formalized these finally only in 2018 with the common cause judgment from the Supreme Court.<sup>[8]</sup>

#### Human rights, UHC and PC

UHC is the idea that all citizens must get quality healthcare that is either free or easily affordable. In the Scandinavian countries, for instance, private healthcare is miniscule since both rich and poor access publicly funded world class services. Beginning with Germany in the late 19<sup>th</sup> century, by the middle of the 20<sup>th</sup>, this was the norm in developed countries. In 1979, UHC was recognized as a basic human right. The socio-political development of a country and provision of UHC often go hand-in-hand. PC grows best where it is supported by UHC because it is difficult to establish it as a viable service in profit driven private healthcare. After its inception in the UK, PC has grown rapidly across the world. The WHO explicitly recognizes PC under the human right to healthcare as an ethical service responsibility.<sup>[9]</sup> PC's rise has been spectacular in the past two decades, especially in large urban areas in affluent countries where it has been supported by academic medical establishments, public awareness of PC, and charitable and volunteer networks. For PC, India is characterized as a "low demand and low supply" country because we have neither UHC nor public awareness of the need for PC.

#### THE NEED FOR NEURO PC

##### The neurologic burden of disease and problems with traditional PC

Public health priorities worldwide were focused on infectious disease and maternal and child health till the 1990s. In the past decade, the neurologic burden of disease has begun to come into focus and detailed reports are now being published by the WHO. It is projected that the burden of serious health-related suffering will double over the next few decades, led by the needs of senior citizens in the low-income countries. Policy makers, including in India, are beginning to respond. The greatest increase will be for dementia: With a roughly 250% rise by 2060! Traditional PC has been focused on cancer, even though Dame Saunders herself pointed out the need to get involved with neurologic illness in the 1960s. This is because cancer victims need physical pain relief and have a voice, both very different from our often silent patients. Oncology also works with a defined disease trajectory and fairly accurate prognosis while neurologic patients' needs can often be interminable. Thus, oncology incorporates palliative and supportive care in a "bow-tie" model<sup>[10]</sup> where cancer specialists' involvement usually fades in the later part of the disease. This does not work for neurology since neurologic care continues till the end. Clinicians dealing with these issues began to publish books and articles on PC in neurology beginning in the early 2000s. The first meetings were held on the sidelines of the American Academy of Neurology annual

meeting, culminating in a summit meeting<sup>[11]</sup> in 2017. This led to the formation, earlier this year of the International Neuropalliative Care Society (INPCS) with the goal of improving the lives of neurologic patients worldwide by the application of PC principles. INPCS welcomes members from all clinical streams and paramedical branches as well as patients and caregivers, individually as well as representatives. We realize that the care of our patients cannot be the responsibility of neurologists alone. Ideally, all neurologists should have basic PC skills and PC clinicians should know the essentials of neurology. NpC is now being recognized as an emerging subspecialty in neurology.

### What does NpC do?

Training in NpC means acquisition of the following knowledge and skill sets.<sup>[12,13]</sup> These can then be deployed in both acute and chronic care settings, in all other neurologic subspecialties such as neurointensive care, stroke, movement disorders, neuro-oncology, neuromuscular medicine, and epilepsy.

1. Assessment of PC needs: The multifarious sufferings of seriously ill patients are best addressed by regular and systematic use of checklists. These are organized as questionnaires. Earlier instruments were designed for cancer and the process of designing and validating these for neurologic illnesses is ongoing
2. Management of Whole Body Pain: Physical symptoms often have to be addressed first, but are often refractory unless psychosocial and spiritual issues are tackled. Basic psychosocial support is best provided by a multidisciplinary team. Spiritual distress may be difficult to identify but a single item "Are you at peace?" has been found effective
3. Communication skills: This requires training, practice, and mentoring but basic rules are simple and easy to learn. More complex interactions need adherence to protocol<sup>[14]</sup> (e.g., SPIKES for breaking bad news). Organizing and running a family meeting for Shared Decision-Making is a crucial skill in neurointensive care
4. Caregiver assessment and support: Our ability to care for our patients depends on the caregiver, who is usually a family member. Assessing caregiver coping, addressing distress, and intervening to prevent burnout are all part of our job
5. Prognostication: Foreseeing and foretelling have been a major part of the physician's duties since the times of Hippocrates. With the advances in diagnosis and therapeutics in the later part of the 20<sup>th</sup> century, we have downgraded this skill. Patients and families desire information on the five Ds: Death, disability/discomfort, disease progression, drug toxicity, and dollars/costs of treatment. In LTNCs, this is best presented as a possible "road map" with signposts of the future decline. In CBL, families need to know best/worst case scenarios for guidance on continuing care versus forgoing (withholding or withdrawing) life support treatments. Comm skills are key to providing this information with honesty, accuracy, and optimism

6. Advance care planning: These instruments are standard across the world for allowing patients to control their past days. Neurologists in the Western world are learning when and how to introduce these topics. They consist of two essential elements: (i) Advance Medical Directives (living wills) specifying the kind of treatment one wants or does not want when one can no longer decide or communicate; and (ii) Healthcare Proxy appointment: The persons (up to three, called on in sequence) who have the responsibility and often discretion of carrying out the individual's wishes. ACP is largely driven by patient awareness but requires policy changes to make it effective. We in India, have just begun this process with the common cause judgment of the Supreme Court in 2018
7. Clinical ethics applications: We are all aware of the pillars of medical ethics: Respect for patient autonomy, non-maleficence, beneficence, and justice. Case based application shows up frequent conflicts between these four essentials. If we look at medical indications for a course of action, we consider beneficence and non-maleficence jointly. Patient autonomy comes to the fore if patient preferences are given primacy and we need to consider if consent is truly informed, in a patient who has decision-making capacity. In the absence of capacity, prior stated choices for life-support treatment and identification of appropriate surrogate decision makers become important. If patient and/or family prioritize QoL then determining and communicating prognosis for recovery and asking what might be an acceptable QoL are needed. There are times when contextual features of the case are important and we need to look at conflicts of interest, the roles and capability of family members and legal/religious/social constraints on decision making. Because our patients are so often vulnerable, this is a major responsibility in NpC
8. End of life (EoL) end of life care: Patient and family preferences should be addressed well before this stage is reached. Patients with severe neurologic/cognitive disability have the right to determine in advance by ACP which if any life supporting interventions are acceptable to them. This requires the NpC clinician to have discussed the disease road map in a timely fashion. Clinically, assisted nutrition and hydration by any route are invasive and can be refused. All of this requires preparation for the final days and weeks as the surviving family goes through the bereavement process. Physical symptoms often need intensive management at this stage and in the absence of hospice services, may need to be done in hospital. NpC clinicians need to be able to carry out or supervise palliative sedation and palliative extubation.

### Prioritizing research and education in NpC

Education is needed to reduce the stigma of PC especially among senior doctors. Younger physicians in India will probably have a better exposure as undergraduates because of the AETCOM modules.<sup>[15]</sup> Standards need to be set in post graduate neurology training so that neurologists can

be primary PC providers for their own patients, utilizing specialist PC only for difficult issues. NpC training should be available to all providers, at all levels (nurses, GPs, and consultants) and for that INPCS proposes to set up an International Course in NpC. This will be run out of India as a blended (online and live teaching) modular program, beginning July 2022. There will be an effort to coordinate joint teaching for all streams so that team work is enabled. At the 2017 summit meeting, the following priorities were identified for research: Epidemiology, outcomes (patient judged, economic, etc.), needs assessment methodology, interventions (including behavioral), implementation/dissemination, and patient/family engagement. As physicians and neurologists, we are aware of quantitative methods in medicine. PC research usually needs the qualitative research methodology that is used by the social sciences.

#### Providing NpC as a service

The following approaches have been used in different situations across the world and in a country as diverse as India, any or all of these models can be used. All of them will have their own organizational and funding challenges. (i) Consultative: Neurologists access specialists in PC and work with them to manage their own patients. At present, PC physicians are too few and we need to prod our systems to set up this service. (ii) Integrated: Neurologists are trained in basic PC and utilize specialist PC physicians/teams as and when needed. (iii) Disease specific: Multidisciplinary teams can be set up for specific conditions with a PC physician as part of the team. This will take the patient from diagnosis, through rehabilitation and till palliation as part of a continuum. (iv) Primary PC: Everybody is trained in basics of PC so that it can be provided from the publicly funded primary health center. (v) Communitarian: The global exemplar for this is the neighborhood networks system of Kerala.<sup>[16]</sup> The government funds the PHC to provide PC but services are delivered by networks of local volunteers. These networks get organizational and programmatic support from NGOs who specialize in PC. Most importantly, the neighborhood decides who is suffering, needs the service and then raises funds/resources locally. When these started in the 1990s, 90% of their case load was cancer. At present, neurologic conditions account for over 50%!<sup>[17]</sup>

#### THE ROAD AHEAD: NPC IN INDIA

Based on the GBD project and the Kerala experience, we can safely guesstimate that about 50% of deaths in India in the near future will be due to neurologic illnesses and conditions or will be dominated by neurologic symptoms. The need for education is thus humungous and cannot be

restricted to neurologists or PC physicians alone. All levels of clinical professionals: Paramedics, nurses, and doctors will need access to the basic training. We will also need to set up training for caregivers (family caregivers, volunteers, and paid care assistants). Public policy and political will are needed to create a cadre equivalent to ASHA workers, but working for the other end of life: Since geriatric, palliative, and dementia care need similar skills. Primary care doctors and PHCs will provide service locally and at home. Ideally, neighborhood networks of volunteers, as in Kerala, will then fill in the gaps.

#### CONCLUSION

Patients with neurologic conditions need application of the basic principles of palliative care, often from the time of diagnosis. This care includes symptom control as part of holistic management of all health related suffering. Care has to be centred on the patient and the family as a unit. Training in neuropalliative care should be available not just to neurologists and neurosurgeons, but to everyone who is responsible, either personally or professionally for a patient with either a long term neurologic condition or serious acute brain injury.

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