

Palliative care and the Indian neurologist

Roop Gursahani

Department of Neurology, PD Hinduja Hospital, Mumbai, Maharashtra, India

Abstract

End-of-life care is an integral part of neurology practice, and neuropalliative medicine is an emerging neurology subspecialty. This begins with serious illness communication as a protocol-based process that depends on an evaluation of patient autonomy and accurate prognostication. Communication needs vary between chronic, life-limiting neurologic illnesses and acute brain injury. In an ideal situation, the patient's wishes are spelled out in advance care plans and living wills, and surrogates have only limited choices for implementation. Palliative care prepares for decline and death as an expected outcome and focuses on improving the quality of life for both the patients and their caregivers. In the Intensive Care Unit, this may require clarity on withholding and withdrawal of treatment. In all locations of care, the emphasis is on symptom control. Neurologists are the quintessential physicians, and our "dharma" is best served by empathetically bringing our technical knowledge and communication skills into easing this final transition for our patients and their families to the best of our ability.

Key Words

End-of-life care, neuropalliative care, serious illness communication

For correspondence:

Dr. Roop Gursahani, PD Hinduja Hospital, Swatantrya Veer Savarkar Marg, Mahim, Mumbai - 400 016, Maharashtra, India.

E-mail: roop_gursahani@hotmail.com

Ann Indian Acad Neurol 2016;19:S40-44

Introduction

Neurology practice is changing. We have moved far away from our mythical past when we were exemplary diagnosticians, announcing complex and untreatable illnesses and syndromes, leaving it to lesser physicians to live with real patients and their ailments. Today, I can expect to age with my multiple sclerosis (MS) and epilepsy patients, share in their growth and decline but also to grieve over their passing. End-of-life care is not just for palliative care and oncology professionals^[1] [Table 1]. In fact, it is an inescapable part of our commitment to our patients. As a specialty are we prepared for this? Do we train our students to "know" their patients to "speak truth" when we communicate diagnosis and prognosis and to "do" empathy with skill and courage? This article attempts to put together the issues that matter in this crucial and neglected part of our professional lives.

Neuropalliative care is a recognized subspecialty in the American Academy of Neurology. Efforts are being made to

establish it in India by providing training and mentorship. Hopefully, India will also soon have a comprehensive end-of-life care legislation that will provide the legal framework to safeguard patients' rights, support the caring physician, and enable the conversations that we must have among families and communities about death and dying.^[2]

Serious Illness Communication

This begins with prognostication. In a landmark study from the USA, Lunney *et al.*^[3] showed that 47% of the Medicare deaths were due to frailty and dementia while organ system failure claimed 16%. In both these categories, statistical tools allow predictions of 1-year mortality. For instance, a male patient, requiring assistance with 1-4 basic activities of daily living, congestive heart failure, and a serum albumin <30 g/L has a 64%

This is an open access article distributed under the terms of the Creative Commons Attribution-NonCommercial-ShareAlike 3.0 License, which allows others to remix, tweak, and build upon the work non-commercially, as long as the author is credited and the new creations are licensed under the identical terms.

For reprints contact: reprints@medknow.com

How to cite this article: Gursahani R. Palliative care and the Indian neurologist. *Ann Indian Acad Neurol* 2016;19:S40-4.

Received: 19-07-16, **Revised:** 04-09-16, **Accepted:** 04-09-16

Access this article online

Quick Response Code:



Website:

www.annalsofian.org

DOI:

10.4103/0972-2327.192885

risk of dying within the next 12 months.^[4] It is appropriate to open the discussion of goals of care whenever an experienced clinician answers “No” to the question: “Would I be surprised if this patient died in the next 1 year?” Not all patients are ready for this conversation,^[5] and it must be seen as a process rather than an end in itself. This process begins with choosing the interlocutor and this can be quite challenging in some situations.^[6] At the earliest possible stage, the patient’s wishes must be elicited. Some patients wish to stay in charge of their care, but others prefer to delegate decision-making. A small minority may find this discussion painful and their wishes must also be respected.^[7] In the Indian context, both families and medical care providers routinely bypass the patient and this infringement of his/her autonomy must be resisted.^[6]

Breaking bad news [Table 2]

The SPIKES (Setting up the interview, assessing patient’s Perception, obtaining patient’s Invitation, giving Knowledge, addressing Emotions, Strategy and Summary) protocol^[8] was devised for delivering bad news in oncology but can easily be appropriated for our needs. Narayanan *et al.* offer a simpler BREAKS (Background, Rapport, Explore, Announce, Kindling, Summarize) protocol.^[9] Facilitation and communications skills are required to set up the meeting. Knowing the patient’s context^[10] is as important as knowing the clinical details, prognosis, and treatment options. Word choices matter and any clinician who expects to perform this task should script and practice using some of the sentences that need to be delivered. The NURSE (Name, Understand, Respect, Support, and Explore emotions) mnemonic can be used as a template for addressing the emotional content of these discussions.^[11] However, empathetic communication can never be standardized. Overscripting carries the risk of detracting from both real and perceived empathy, especially if a disconnection between verbal and nonverbal communication creates a discomfiting “uncanny valley.”^[12] Indications of serious illness communication (SIC) are shown in Table 3.

SIC needs to be addressed differently in patients with chronic, life-limiting neurologic illnesses as opposed to acute brain injury [Table 2]. In the former, SIC will be initiated at the time of diagnosis for motor neuron disease (MND) and malignant cerebral tumors. These conversations can begin by assessing the patient’s own level of knowledge. The disease should be identified clearly and concisely after seeking permission for beginning this discussion. Patient and his/her family must be allowed time to process this news, including seeking other opinions and reading about the illness. The initial SIC encounter should end with the proposal of a follow-up consultation to discuss prognosis and future options. For Parkinsonism and MS, event-driven milestones (e.g., increasing symptoms, deteriorating the quality of life) can be used as SIC triggers. Epilepsy is a special situation where sudden unexpected death in epilepsy and accidental death may be discussed during follow-up visits, once rapport is established.

Acute brain injuries such as stroke require a different approach since the patient cannot be expected to participate. In addition to informing the family, the clinician must also check if the patient had expressed any wishes regarding the goals of care and life-sustaining therapies. Although advance care plans are still not legally valid in India, this is a situation that may

Table 1: Why neurologists need palliative care skills^[1]

Care of complex patients over time
Frequent hospital admissions for the same diagnosis of a serious illness
Addressing complex depression, anxiety, grief, and/or psychosocial distress
ICU admission with a poor prognosis
Prolonged ICU stay
Combining medical decision-making with determining goals of care
Discussing transitions in care, for example, from ICU to home
Complex and/or evolving goals of care discussions
Assistance with conflict resolution
Redefining hope in the setting of complex illness
Ethical dilemmas
Determining present and future care needs
Determining and discussing prognosis
Preterminal care and planning, including death
Discussing issues pertaining to artificial feeding and hydration

ICU = Intensive Care Unit

Table 2: Breaking bad news. Suggested plan, incorporating elements of SPIKES, BREAKS, and NURSE^[8,9,11]

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
What does the patient/family know already?
“What have you been told? What do you understand?”
Note vocabulary, comprehension, denial
Does the patient/family want to know?
Check willingness with explicit question
If declined, leave option open for future
Give information
Align: keep to recipient’s level of comprehension
Educate: preferably not more than three pieces of information
Dealing with emotions and reactions (NURSE)
Name and understand the emotion
Respect and support the emotion
Explore the emotion
Deal with strong reactions: crying, anger, etc.
Closing
Summarize
Express personal support
Check for safety, suicidal ideation
Fix plans for the next meeting

NURSE = Name, Understand, Respect, Support, and Explore emotions, BREAKS = Background, Rapport, Explore, Announce, Kindling, Summarize, SPIKES = Setting up the interview, assessing patient’s Perception, obtaining patient’s Invitation, giving Knowledge, addressing Emotions, Strategy and Summary

evolve. Empathetic communication is vital for establishing a partnership so that decision-making can be shared with the patient’s surrogates. If the patient had clearly expressed his/her wishes for limitation of care and if it is medically appropriate, the treating team can affirm that those wishes will be respected and thus provide emotional closure for the family. The crucial factor here is prognostication. It is now well known that

Table 3: Indications for serious illness communication^[11]

General	
Age >80 years and hospitalized	
Patient or family asks to discuss these issues	
Would you be surprised if patient died in the next year?	
Acute brain injury	
Predicted major functional and/or cognitive deficits requiring long-term assistance	
Requiring long-term artificial nutrition	
Motor neuron disease	
Dysphagia and considering artificial nutrition	
Hypoventilation and considering noninvasive or long-term mechanical ventilation	
Malignant brain tumor	
At diagnosis, if cognitive or communication impairment is likely with progression	
Second-line chemotherapy	
Dementia, parkinsonism	
Requiring support on 3-4 basic ADLs	
Decreased/insufficient nutritional intake	
Other important comorbidities (stroke, cancer, and congestive heart failure)	

ADLs = Activities of daily living

institutional policies regarding treatment limitation significantly impact mortality, for instance, in intracerebral hemorrhage.^[13]

Advance Directives

Advance care planning^[14] refers to a process of considering, discussing, planning, and communicating one's health-care treatment and 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. Nonmedical 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. ADs are legally valid and enforceable in most Western democracies but not yet in India.^[2]

Components

The available templates have evolved, as medical care and Intensive Care Unit (ICU) options became more complex.^[15] The simplest comprehensive set is the "Five Wishes" from Aging with Dignity.^[16] They include: (a) the person I want to make care decisions for me when I cannot, (b) the kind of medical treatment I want or do not want, (c) how comfortable I want to be, (d) how I want people to treat me, and (e) what I want my loved ones to know. More comprehensive and legally worded ADs are available on the Internet.^[17] This example states that "if I have an end-stage medical condition (which will result in my death despite the introduction or continuation of medical treatment) or am permanently unconscious with irreversible coma or vegetative state and there is no realistic hope of meaningful recovery, all the following apply... then I specifically do not want any of the following...." This is accompanied by a list of life-prolonging treatments such as cardiopulmonary resuscitation, mechanical ventilation, hemodialysis, surgery, chemotherapy, and radiotherapy, which are individually ticked.

Determining Competence

Neurologists can be called upon to opine on decision-making capacity (DMC) for the standard legal wills.^[18] DMC is not an all-or-nothing phenomenon and can be clinically certified even in the presence of mild-to-moderate dementia. Ideally, it should be determined by the patient's own physician, and a neurologist may be required only to do a cognitive assessment. It is conceivable that a patient with mild cognitive impairment, early dementia, or stroke might request counseling for preparing an AD.

Palliative and End-of-life Care

Palliative care has been defined as "specialized medical care for people with serious illnesses. This type of care is focused on providing patients with relief from the symptoms, pain, and stress of a serious illness—whatever the diagnosis. The goal is to improve the quality of life for both the patients and their family." Palliative care also differs from traditional care in accepting and planning for decline and death as an expected outcome of illness.^[19]

Symptom management

Patients with Parkinson's disease, MS, and MND can be significantly afflicted by nonmotor symptoms such as pain, depression, anxiety, fatigue, sleep, constipation, urinary urgency, and sexual dysfunction, and through the course of a long illness, these probably affect the quality of life more than the motor disability. All cognitively impaired patients can develop behavioral and psychiatric symptoms that increase caregiver burden.

In the Intensive Care Unit

Most of us do not understand the full impact of ICU care on someone who is past the point of benefitting from it.^[20] Withholding and withdrawal of life-supporting treatment and "do-not-resuscitate" orders precede most deaths of adults and 40%–60% of deaths in children in Europe and North America.^[2] The situation is significantly different not only in India but also across Asia, and physicians' attitudes are possibly the biggest barriers here. This was shown by a structured and scenario-based survey of 1465 physicians in 466 ICUs over 16 Asian countries and regions.^[21] The authors showed that refusal to implement do-not-resuscitate orders was more likely with physicians who did not value families' or surrogates' requests, who were uncomfortable discussing end-of-life care, and who perceived greater legal risk in low-to-middle-income economies. Indian "jugaad" comes through in our innovation of "LAMA/DAMA," the unconscious patient who departs, i.e., "left/discharged against medical advice," usually to die a tortured death without appropriate palliative care. I believe that even in situations of significant financial limitation, a responsible, caring physician can and should avoid this situation.

At home

Worldwide, most people when asked, prefer to die at home and Indians are no different.^[22] The question "where do you want to pass your last days: at home or in a hospital?" acts as a powerful framing device to bring the whole context of the SIC into a sharp focus for the patients and their family. However, dying

at home is not easy in India: an evocative blog post by Chopra makes this very clear.^[23] She speaks of the difficulties faced by a Dehradun family when they decided to let their mother pass away in peace in her own bed. The major difficulty is the lack of palliative care support, which is obvious since this is such a nascent specialty. Neurologists can make a contribution by giving basic guidelines for care of the dying at home [Table 4]. However, a less obvious problem is to find a family practitioner who is willing to issue the death certificate, and families must be warned to prepare for this in advance. Kerala is the only state where these issues usually do not arise because of the efforts of Pallium India.^[24]

Care giver assessment and support

The physician must take care at some stage to express his/her understanding and support for the caregiver and his/her burden. Support groups are very helpful in this situation as they can provide counseling and useful tips. It is useful to explore family dynamics and perhaps attempt to organize respite periods. Toward the end, bereavement counseling may also be required.

Neurology in a Changing India

Earlier generations grew up with a faith in an omnipresent family and an unchanging India. East Asia gives us some

Table 4: Comfort care: a checklist for the responsible physician

Oral care
Brush teeth with soft brush after meals or BID
Saline oral rinse or clean with soaked gauze 2 hourly
Candid mouth paint: TID, after food
Disorientation
Ample natural light, visible calendar, and clock
Stick to normal timings, read out daily news
Hallucinations/agitation: haloperidol 0.5-1 mg PO, HS
Skin care
Bed sore precautions
Regular massage
Moisturizing cream over dry areas
Breathlessness
Facial cooling with fan, open windows, elevate head end of bed, nebulize
Nasal oxygen: adjust till comfortable
Clonazepam: sublingual, 0.5-1 mg, for panic
Oral morphine: 2.5 mg (1/4 of 10 mg tablet) QID
Subcutaneous midazolam 1 mg increments or IV morphine 2-4 mg for every 30 min till comfortable
Pain
Ask patient level of pain on 1-10 scale
Mild-moderate (pain level 1-3): paracetamol (up to 3 g/day except in liver failure) or NSAIDs
Moderate-severe (pain level 4-10): morphine oral up to 10 mg hourly, IV up to 2-5 mg for every 30 min
Neuropathic pain: gabapentin/pregabalin with dexamethasone
Death rattle
Family re-assurance that there is no distress
Glycopyrrolate: oral 0.5 mg TID

NSAIDs = Nonsteroidal anti-inflammatory drugs, IV = Intravenous

idea of how rapid economic growth impacts demographics.^[2] Because of the skewed sex ratio, 20 years from now, 10% of men in China will not find brides. In Tokyo and Hong Kong, about 20% of women above 35 years are single and are not expected to marry. Single person households constitute 25% of the total in South Korea as compared to 15% in China and 5% in India. Indian society is deeply uncomfortable with individual choice, but personal autonomy is the first principle of bioethics. As physicians, we carry the burden of this dilemma. It is our duty, as far as possible, to help our patients to take charge at the end of their lives.^[6] Often, this requires a social history that allows us to understand the context of their lives and the ensemble around them. Hence, when these decisions have to be made, we should be able to intervene appropriately and ensure that a competent patient has the opportunity to find about his/her illness, the likely outcome, and to make her choices through an open discussion with his/her family and the treating team. We have to also express our support as the end draws near. As physicians, we uphold the dignity and "dharma" of our profession by not rejecting, but instead embracing this often deeply personal and professional challenge. Done right, this provides emotional closure for the patient, his/her family, and his/her physician.

Financial support and sponsorship

Nil.

Conflicts of interest

There are no conflicts of interest.

References

1. Strand JJ, Kamdar MM, Carey EC. Top 10 things palliative care clinicians wished everyone knew about palliative care. *Mayo Clin Proc* 2013;88:859-65.
2. Gursahani R, Mani RK. India: Not a country to die in. *Indian J Med Ethics* 2016;1:30-5.
3. Lunney JR, Lynn J, Hogan C. Profiles of older Medicare decedents. *J Am Geriatr Soc* 2002;50:1108-12.
4. You JJ, Fowler RA, Heyland DK; Canadian Researchers at the End of Life Network (CARENET). Just ask: Discussing goals of care with patients in hospital with serious illness. *CMAJ* 2014;186:425-32.
5. Ishaque S, Saleem T, Khawaja FB, Qidwai W. Breaking bad news: Exploring patient's perspective and expectations. *J Pak Med Assoc* 2010;60:407-11.
6. Gursahani R. Communicating truth about serious illnesses in the Indian context. *Natl Med J India* 2015;28:269-71.
7. Braun UK, Beyth RJ, Ford ME, Espadas D, McCullough LB. Decision-making styles of seriously ill male Veterans for end-of-life care: Autonomists, altruists, authorizers, absolute trusters, and avoiders. *Patient Educ Couns* 2014;94:334-41.
8. Baile WF, Buckman R, Lenzi R, Glober G, Beale EA, Kudelka AP. SPIKES-A six-step protocol for delivering bad news: Application to the patient with cancer. *Oncologist* 2000;5:302-11.
9. Narayanan V, Bista B, Koshy C. "BREAKS" protocol for breaking bad news. *Indian J Palliat Care* 2010;16:61-5.
10. Weiner S, Schwartz A. *Listening for What Matters: Avoiding Contextual Errors in Health Care*. Oxford: Oxford University Press; 2016.
11. Creutzfeldt CJ, Robinson MT, Holloway RG. Neurologists as primary palliative care providers: Communication and practice approaches. *Neurol Clin Pract* 2016;6:40-8.
12. Gardner C. Medicine's uncanny valley: The problem of standardising empathy. *Lancet* 2015;386:1032-3.
13. Zahuranec DB, Fagerlin A, Sánchez BN, Roney ME, Thompson BB, Fuhrel-Forbis A, *et al*. Variability in physician prognosis and

- recommendations after intracerebral hemorrhage. *Neurology* 2016;86:1864-71.
14. Lum HD, Sudore RL, Bekelman DB. Advance care planning in the elderly. *Med Clin North Am* 2015;99:391-403.
 15. Miles S. Unadorned: My Testament. Available from: <http://www.bioethics.net/2016/02/unadorned-my-testament/>. [Last accessed on 2016 Jun 22].
 16. The Five Wishes Document. Available from: <https://www.agingwithdignity.org/docs/default-source/default-document-library/product-samples/fwsample.pdf?sfvrsn=2>. [Last accessed on 2016 Jun 22].
 17. Pope T. Sample Advance Directive. Available from: http://www.thaddeuspope.com/images/Thaddeus_Pope_Adv_Dir.pdf. [Last accessed on 2016 Jun 22].
 18. Jacoby R, Steer P. How to assess capacity to make a will. *BMJ* 2007;335:155-7.
 19. Boersma I, Miyasaki J, Kutner J, Kluger B. Palliative care and neurology: Time for a paradigm shift. *Neurology* 2014;83:561-7.
 20. Rajagopal MR. Don't Torture the Dying. Available from: www.blogs.timesofindia.indiatimes.com/toi-edit-page/dont-torture-the-dying-health-ministrys-draft-law-confuses-between-euthanasia-and-withdrawal-of-life-support/. [Last accessed on 2016 Jun 22].
 21. Phua J, Joynt GM, Nishimura M, Deng Y, Myatra SN, Chan YH, *et al*. Withholding and withdrawal of life-sustaining treatments in intensive care units in Asia. *JAMA Intern Med* 2015;175:363-71.
 22. Kulkarni P, Kulkarni P, Anavkar V, Ghooi R. Preference of the place of death among people of Pune. *Indian J Palliat Care* 2014;20:101-6.
 23. Chopra J. India: Not a Country to Die in. Available from: <http://www.lataroy.org/jo/2015/10/india-not-a-country-todie-in/>. [Last accessed on 2016 Jun 22].
 24. The Quality of Death. Ranking End of Life Care across the World. A Report of Economic Intelligence Unit, Lein Foundation; 2010. Available from: http://www.virtualhospice.ca/Assets/Quality%20of%20Death%20Ranking%202010_20100915182153.pdf. [Last accessed on 2016 Jun 22].