

A Palliative Care Approach to End-stage Neurodegenerative Conditions

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Abstract

Introduction: Neurodegenerative conditions, such as Alzheimer's disease, Parkinson's disease and motor neurone disease, are progressive and incurable conditions that ultimately lead to a state of total functional incapacitation and death. These conditions are "terminal" and, therefore, should be managed with a palliative care approach. This article highlights some of the issues in caring for patients with end-stage neurodegenerative conditions from a palliative perspective. **Methods:** This review is based on evidence from pre-existing medical literature on the above subject and the authors' personal experiences and observations. **Conclusion:** Patients with end-stage neurodegenerative conditions have needs similar to that of advanced cancer patients. Therefore, the principles and practice of palliative care should be applied to such patients. This may also mean that palliative care training should be undertaken in nursing homes, where a large number of such patients are located.

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Introduction

A syndrome of total functional dependence, poor mobility, lack of meaningful communication and incontinence of bowels and bladder appears to be the final common pathway for many neurodegenerative conditions such as the dementias, Parkinson's disease (PD) and motor neurone disease (MND). In the United States, the National Hospice Organisation (NHO) has outlined a set of criteria for hospice care in end-stage dementia, where patients who are non-ambulant without assistance, require assistance in all activities of daily living, unable to communicate meaningfully and have bladder and bowel incontinence qualify for palliative care funding.¹ This state corresponds to stage 7 of the functional assessment staging classification (FAST) by Reisberg,² which carries a prognosis of about 6 months. For patients with such conditions, who are old and have multiple comorbidities, the progress towards death may be complex and unpredictable, thus casting into doubt the suitability of such patients for palliative care.³ The dying trajectory may be punctuated by a series of acute illnesses that require more aggressive measures or treatment.⁴ Sidell et al⁵ classified the possible modes of

death for such patients into four groups: sudden death, death following a terminal illness, death following an acute illness or death following a general deterioration in condition.

Numerous studies have shown that, when given a scenario of end-stage dementia or chronic physical illnesses, most subjects would choose a palliative care approach to treatment for themselves and their loved ones.⁶⁻⁸ This is an approach that emphasises symptom control, holistic care and quality of life over cure, aggressive and life-prolonging therapy.

This article describes management issues in the care of patients with end-stage neurodegenerative disorders. It approaches the subject from a geriatric and palliative medicine perspective and, in so doing, illuminates the many common and shared goals of the 2 disciplines.

The Common Ground

Palliative care deals with patients whose diseases are not responsive to curative treatment, where control of pain and other symptoms as well as of psychological, social and spiritual problems, is paramount.⁹ The principles of care are based on a whole-person approach utilising the expertise

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of a multi- or interdisciplinary team, with the goal of achieving the best quality of life for the patient. The unit of care is the patient and his family.

Geriatric medicine deals with patients who are in the last stage of their lives. These patients may range from the active and independent to the frail with multiple comorbidities. Just as in palliative care, a holistic and multidisciplinary approach is taken in the usual geriatric assessment process and the emphasis is, again, on quality of life.¹⁰ However, in the broadest sense, geriatric medicine encompasses a wide spectrum of care ranging from acute to end-of-life care. As one approaches the end of the spectrum, clinical care approximates that of palliative care (Fig. 1). Geriatric medicine stands at the interface between acute medicine and palliative care. Whereas in the early stages care is targeted at prevention, cure and even increased survival, the later stages aim at comfort measures and best supportive care, not quite dissimilar from palliative care.

The neurodegenerative conditions, such as dementia, embody a concept of care that straddles the geriatric and palliative care milieu. In the early stages, when the patient is still independent, treatment is more cure-oriented and aggressive; whilst in the later stages, treatment is palliation-oriented and more supportive in nature.

Natural Progression of Neurodegenerative Illnesses

These conditions are generally incurable and invariably take on a progressive course, though at differing rates. In dementia, the time from diagnosis to death ranges from 7 to 15 years but averages about 10 years.^{1,11-13} Mortality from PD remains high compared to the general population¹⁴⁻¹⁶ even though survival may be increased by about 5 years in younger patients on levodopa. The use of levodopa, however, is not known to alter significantly the natural progression of the disease.¹⁷

Cognitive impairment is fairly common in PD and it occurs in about 19%¹⁸ of patients while dementia occurs in

the later stages of the illness in approximately 16% to 32%¹⁸⁻²¹ of patients. A recent 8-year prospective study observed the presence of dementia in nearly 80% of a cohort with PD.²² While dementia, excluding the vascular causes, presents initially with cognitive problems leading to motor problems in the later stages of the illness, PD manifests initially with motor problems that progress later to include cognitive problems, so that the end-stage of both conditions appear confluent. The incidence of cognitive deficits is low in MND, but is present in a sizable minority.²³

There is progressive loss of mobility and loss of ability for self-care. The patient becomes bedbound, develops limb contractures and is at risk of developing pressure areas and ulcers. Feeding is impaired as a result of the inability to bring food to the mouth or dysphagia from neurological deficits. Consequently, the patient's nutritional status deteriorates. In many instances feeding tubes are used to ameliorate the problem, but this inadvertently leads to additional problems such as aspiration pneumonia, discomfort and the need for restrainers in certain extreme situations. Bowel and bladder incontinence develops and the patient may need long-term catheterisation and incontinence pads. In the final stages, the patient becomes mute and unable to communicate meaningfully. A vegetative state ensues towards the end and this may persist for months to even years.

Against this backdrop of a slow and progressive illness, there are recurrent acute episodes of infections involving the lung, urinary tract, biliary tract and skin, any of which could bring about the patient's demise.

Prognosticating and estimating life expectancy is one of the more important practices of palliative care. Most patients with a terminal illness would choose to know the amount of time left for them to live so that they would be able to make timely adjustments and preparations. Estimating life expectancy is sometimes important for funding purposes and in assessing suitability for admission to certain hospice services. In chronic end-stage neurodegenerative conditions where disease progression is variable, predicting life expectancy can be extremely difficult. These conditions may take a relatively stable course that is punctuated by acute life-threatening events, which ultimately result in death. Which of the many recurrent acute events that eventually causes death is difficult to ascertain.

Alzheimer's patients in the FAST 7C state, who have comorbidities related to loss of functional status, such as infections, decubitus ulcers and deteriorating nutritional state, would usually be expected to pass away within 6 months to a year.²⁴ Predicting the prognosis for end-stage MND can be even more challenging as recent technological advances have made it possible to sustain the patient's ventilatory and nutritional status for prolonged periods of

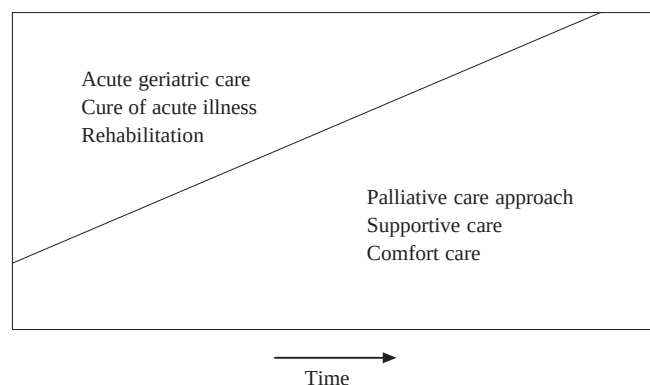


Fig. 1. Schema of approach to managing patients with neurodegenerative conditions over time. [Source: Twycross R (2001). *Symptom Management in Advanced Cancer* (3e). Radcliffe Medical Press, Oxford].

time. Moreover, the rate of deterioration in such patients varies according to each individual. Despite these, however, a large number of MND patients are unable to afford the cost of such interventions or would choose to forego the burden of living with feeding tubes, ventilators and other gadgets; for such patients, a palliative care approach would be appropriate. In addition, a rapidly progressive disease, critically impaired ventilatory status or other life-threatening complications such as infections denote a poor prognosis.¹

The psychosocial implications of an uncertain prognosis and life expectancy are discussed later. Suffice to say that in caring for patients described above, it is imperative that one adopts a holistic and multidimensional approach (Table I).

Physical Issues

Symptoms can occur as a result of underlying comorbidities or intercurrent acute illnesses such as infections or cardiovascular events. The following are some of the more common symptoms and problems that occur in those with advanced neurodegenerative conditions:

Loss of Function and Immobility

One of the most consistent problems in patients with end-stage neurodegenerative conditions is the total loss of

function and immobility at a relatively early stage of the palliative care phase of care. In advanced cancer, this state is reached late in the terminal phase, which can range from days to weeks; in advanced neurodegenerative conditions the patient may be in this state for months to even years. The common problems of decubitus ulcers, contractures, predisposition to infections, bowel and bladder incontinence/retention become major issues that need to be contended with. Recurrent infections in the lungs (aspiration pneumonia), urinary tract, biliary tract and skin can be burdensome and bring about significant suffering for the incapacitated patient and his caregivers. The use of antibiotics in terminal care is not absolutely contraindicated as it has a role in alleviating symptoms associated with the infection such as the pain from cellulitis and secretions from pneumonia.²⁵ Here, the role of antibiotics is purely to provide relief from symptoms, as opposed to its curative effects, which some studies have found to be limited in end-stage dementia.²⁶⁻²⁸ In considering the use of antibiotics, one must take into account the patient's estimated life expectancy, the issue of futility and the burden that antibiotic treatment imposes on the patient.

Pain

Pain is a symptom that is frequently underdiagnosed and, therefore, undertreated in patients who are unable to communicate effectively or are cognitively impaired.²⁹⁻³¹ Even among well community-dwelling older people, the prevalence of pain ranges from 25% to 50% and arises mostly from arthritis, back problems and other bone and joint disorders, which are more common in this age group.^{32,33} Pain is estimated to occur in 40% of patients with PD and can be categorised into musculoskeletal, dystonic, neuritic, akathitic or central pain.³⁴ In view of the mechanical nature of most pain in this group of patients, one must be vigilant in looking out for incident pain which is more pronounced, especially at the time of nursing procedures. In severely demented patients, the expression of pain (pain behaviour) may be blunted. Nonetheless, pain may manifest atypically as increased confusion, loud vocalisations, moaning, grimacing, restlessness, agitation, posturing or even withdrawal. The PD or MND patient, on the other hand, may not display some of the usual pain behaviour such as grimacing or posturing. The assessment of pain can be extremely difficult given these scenarios and the usual pain scales cannot be relied upon to make an accurate assessment. The DOLOPLUS scale attempts to overcome the problem of pain assessment in the older individual by using more objective measures of the patient's reaction to pain.³⁵

As alluded to earlier, pain may also originate from intercurrent problems, such as pleuritic pain from pneumonia, bladder spasms from cystitis, inflammation of an infected pressure sore and osteoporotic fractures.

TABLE I: MULTIDIMENSIONAL ISSUES OF PATIENTS WITH END-STAGE NEURODEGENERATIVE CONDITIONS

Physical
Functional impairment
Symptoms
Complications of immobility
Comorbidities
Nutrition
Psychiatric and behavioural problems
Agitation
Confusion
Disruptive behaviour
Delusions
Hallucinations
Depression
Psychosocial
Burden to carers
Social abandonment
Isolation
Elder abuse
Placement and care issues
Ethical
Advanced care planning
Foregoing interventions
Informed consent
Determination of competence

Breathlessness

Breathlessness is a symptom that has a profound impact on the patients well-being or quality of life. Although, to a large extent, the experience of breathlessness is subjective, there are external signs that may indicate its presence, such as tachypnoea, hyperpnoea, wheezing and throat secretions. The causes of breathlessness in this group of patients include acute problems such as bronchopneumonia, acute pulmonary oedema, pleural effusion or bronchospasm, with or without underlying chronic congestive heart failure, chronic obstructive lung disease or chronic renal failure. Poor nutrition, lack of mobility and lack of exercise lead to respiratory muscle wasting, which contribute to dyspnoea and this may be unmasked by an acute event. A common cause of breathlessness is iatrogenic overhydration (parenterally or enterally) of the patient, leading to pulmonary oedema. In the patient with MND, progressive muscle atrophy can lead to profound breathlessness and respiratory failure. Throat secretions can accompany patients with bronchopneumonia and bronchospasm, which exacerbates the breathlessness. This problem is more acute in patients with MND who are unable to expectorate effectively and may present with choking episodes.

Oedema

Patients who are immobilised over prolonged periods are prone to developing oedema of the upper limbs, lower limbs and trunk. This is compounded by comorbidities such as heart failure, renal impairment and hepatic impairment. Hypoalbuminaemia from chronic illnesses and poor nutrition is also a major precursor of oedema in this group of patients. Oedema leads to skin fragility and increased susceptibility to cutaneous infections.

Skin Problems

Dry skin or xerosis is the most common skin problem in the older person that can cause significant discomfort from pruritus and consequent excoriation.³⁶⁻³⁸ Left untreated, it may lead to secondary inflammation, asteatotic eczema and superimposed cutaneous infections. Xerosis, combined with poor skin circulation, immobility, urinary and faecal incontinence and increased skin fragility, predisposes this group to pressure ulcers. Other common skin conditions include scabies, chronic eczematous lesions, herpes zoster and drug rashes.

Loss of Weight and Poor Nutrition

Loss of weight, wasting and poor nutrition, the *sine qua non* of advanced malignancies, are frequently found in late-stage neurodegenerative disorders.^{39,40} Impaired feeding, as discussed earlier, coupled with diminished caloric requirement, poor dentition, loss of lean body mass and aversive feeding behaviour contribute to weight loss in the older person. Poor nutrition causes physiological changes,

such as lymphopaenia and decreased protein synthesis, leading to the inability to rebuild wasted muscles or to effectively fight off infections. An example would be a wasted individual's inability to cough effectively during a chest infection, leading to retained secretions and pneumonia. In advanced dementia, eating is the last activity of daily living to be impaired⁴¹ and this usually heralds the onset of the terminal phase of illness.⁴² The aversion to food and dysphagia frequently found in this group of patients has social, cultural and ethical implications. The use of feeding tubes is more common in this group as opposed to advanced malignancies. In some ways, this is due to the less predictable course of the underlying illness. Feeding tubes can pose problems of their own such as repeated removal of the tube by the confused patient, excoriation of the anterior nares, aspiration pneumonia, overhydration and diarrhoea.⁴³ From a quality of life perspective, feeding tubes prevent the enjoyment of food and its tastes.

Impaired Excretion

Constipation, urinary retention, faecal incontinence and urinary incontinence are common problems in those with end-stage neurological conditions.^{44,45} While the neurological deficits themselves contribute directly to these problems, poor mobility, impaired cognition, behavioural problems and drug-related side effects, especially from anticholinergic drugs, accentuate the problem further. Cognitively impaired patients with urinary and faecal retention may present instead, with agitation and confusion, which will not settle until these are dealt with.

Oropharyngeal Problems

Oropharyngeal conditions that frequently occur include dental caries, halitosis, candidiasis, ulcers, stomatitis, gingivitis and xerostomia. These conditions may also lead to poorer motivation to eat and, subsequently, malnutrition.

Psychiatric and Behavioural Issues

In early dementia when insight is maintained, there is a greater incidence of anxiety and depression, but these give way to agitation, restlessness and confusion towards the later stages as insight declines.⁴⁶ Agitation and delirium tend to be recurrent and are often associated with, or worsened by, intercurrent acute problems. Delusions, hallucinations and paranoid ideation are other psychiatric symptoms that can occur in the patient. Other behavioural and psychiatric conditions include aggressiveness, aberrant motor behaviour, loud vocalisations, disinhibition and reversal of sleep pattern.⁴⁷ In PD patients who are non-demented, the incidence of anxiety, depression and sleep disturbance is also fairly common.⁴⁸ About 40% of MND patients have insomnia and sleeping difficulties in the last month of life.⁴⁹

Disruptive and uncooperative patients, such as those described above, place a great strain on family members and caregivers, and make optimal management and treatment difficult. In the past, such patients were usually put on physical restraints, ostensibly to facilitate care, prevent falls, avoid pulling out of feeding tubes (used for nutrition and medications) and catheters as well as to prevent the agitated patient from injuring himself.⁵⁰ It is now known that physical restraints, in reality, bring about the iatrogenic effects of immobility, cause social and sensory deprivation, worsen the patients combativeness and insult the patient's dignity.⁵¹

The management of behavioural and psychological problems is integral to palliative care of patients with neurodegenerative conditions as the former occur commonly, in contrast to cancer care where terminal restlessness occurs but usually towards the end of the patient's life.⁴⁸ Nonetheless, as the end draws near, patients with advanced dementia and PD may be totally passive, uncommunicative and mute.

Psychosocial and Ethical Issues

Because of the protracted and unpredictable course of the disease process, late-stage neurodegenerative illnesses place an immense strain on caregivers.⁵² The daily routine of caring and nursing the patient, without ever knowing when the endpoint might be, exerts a burden that can isolate the caregiver and predisposes him or her to physical and psychiatric problems.^{53,54} Loneliness, low morale and depression in caregivers can occur and can sometimes lead to issues of elderly abuse and "granny dumping" or even the "Munchausen by proxy" syndrome.

Strained relationships within the family, especially between those directly caring and those not caring for the patient can also occur. Family members who are not caring for the patient tend to underestimate the degree of care required. There are also feelings of guilt and unresolved personal issues between the patient and family members that can cloud decision making. It is not uncommon for the "carer" to easily come to a decision to "not treat an acute infection" and a "non-carer" to demand treatment, thus causing conflict in decision making.

Existential and spiritual issues constitute an important domain in the care of dying patients with advanced cancers. In end-stage dementia, it is the caregivers and family members who have to contend with these issues. Many caregivers seek to identify meaning in the past, present and future as they are faced with the imminent death of a loved one.⁵⁵ Many are reminded of their own vulnerability and mortality. Seeing a parent slowly deteriorating from a position of strength to a position of total dependence and frailty, the slow and gradual disintegration of the personality and intellect, and the degradation of the person's dignity

can be daunting for the caregiver.

The experience of grief and bereavement by close family members of those with end-stage neurodegenerative illnesses, however, may not be as acute as the patient dying from advanced cancers. This is because the dying trajectory of the former usually takes a prolonged course, provided that it is not abruptly disrupted by an acute illness. This gives time for caregivers to grieve in advance of the actual death (anticipatory grief) and makes acceptance of the eventual demise easier to bear. Albinsson and Strang⁵⁵ described how some relatives referred to such patients as "the living dead". There is gradual disengagement as the family members come to terms and learn to accept the reality of their loved one's slow progression towards the inevitable. Most of these patients are in the older age group and would have lived life to its fullest.

When treating patients who are frail, dependent and cognitively impaired, one is often faced with a multitude of ethical dilemmas. Withholding and withdrawing potentially life-prolonging interventions, artificial nutrition and hydration, do-not-resuscitate orders and requests for euthanasia are just some of the issues that one has to grapple with in the course of managing such patients. These are the same issues that beset the caregivers of patients with terminal cancers.⁵⁶ Advance care planning (ACP) is a means by which the patient states his or her preferences for specific end-of-life care and medical interventions. This should be carried out while the patient is still mentally competent and is able to make decisions for himself or herself. ACP is the process of planning for future medical care, where the patient's values and goals are explored and documented and a proxy decision maker is determined.

In those who are cognitively impaired, the determination of mental competence and decision-making ability, which is closely linked to the issue of informed consent, is important to avoid legal and ethical pitfalls. Competence assessments serve 2 goals: protecting decisional autonomy for some individuals whilst identifying those who may require protection from harm.⁵⁷

Palliative Care in the Nursing Homes

As the population ages, more people can expect to spend their last days in nursing homes. In 1997, nearly 25% of Americans died in nursing homes (NHs) and this figure is expected to increase to 40% by the year 2020;⁵⁸ while in the United Kingdom, this figure stands at 18%.⁵⁹ There are no local figures available at this point in time but, conceivably, many patients with end-stage neurodegenerative illnesses would end up in NHs where treatment of the terminally ill and those with non-cancer illnesses may be inadequate. Several studies have shown that the dying in NHs have poorly-controlled symptoms, and limited spiritual and

emotional support.⁶⁰ A case in point is the inadequate assessment and treatment of pain in NHs where nearly one quarter of residents who experience daily pain do not receive any analgesics and those less likely to receive analgesics usually had cognitive impairment, were older than 85 years or were members of racial minority groups.^{61,62}

Studies by Parker-Oliver et al⁶³ and Miller et al⁶⁴ comparing hospice and non-hospice NH residents observed that the former received better pain management, more treatment for depression and anxiety, fewer hospitalisations, less dyspnoea, fewer invasive procedures and were more likely to have made some advance care planning. Hence, NHs with no hospice care available tend to have suboptimal and inadequate end-of-life care.

From the preceding discussion, it would seem almost intuitive that NHs, which stand at the interface between continuing care for older people and palliative care,⁶⁵ be made to provide palliative care to residents who require it, regardless of whether they are cancer or non-cancer patients. Factors that challenge the delivery of high quality palliative care in these settings include inadequately trained staff, isolation of NHs from the healthcare system, insufficient manpower, lack of support for staff caring for dying residents, accreditation regulations which, as an illustration, fail to recognise functional decline and weight loss as part of the dying process in the elderly and reimbursement policies.⁶⁶

Conclusion

With a rapidly ageing population worldwide, there will be an increase in the number of patients with end-stage degenerative diseases, such as dementia, PD and MND. The number who die from such conditions will rise correspondingly.

It is important to appreciate the terminal nature of such conditions and to adopt a more humane approach when managing patients with these conditions. The technological imperative that compels us at times to provide inappropriate or disproportionately aggressive treatment to the frail patient gives families the notion that medicine can cure all, and that life is to be prolonged at all cost. Families may think it terrible to die with all the tubes and lines *in situ* and may conclude that euthanasia would be an appropriate means to afford a painless and more dignified way of dying to the patient.

Because of the increasing number of older people receiving end-of-life care in nursing homes, a more concerted approach should be taken to ensure that good palliative care is made available in such settings. Palliative and hospice care services should also be expanded in scope to deal with such patients, the “living dead” or the

“disadvantaged dying”.⁶⁷ And perhaps, all training in geriatrics should also include a module on palliative care and *vice versa*.

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