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978-0-521-67249-8 - Palliative Neurology

Ian Maddocks, Bruce Brew, Heather Waddy and Ian Williams

Excerpt

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SECTION I

Palliative Management

Introduction to palliation

PALLIATION, PALLIATIVE CARE AND PALLIATIVE MANAGEMENT

These related terms can be distinguished individually.

To use an analgesic for relief of pain, to inject insulin to control diabetes, to inject botulinum toxin for relief of torticollis is to *palliate*, to provide temporary relief.

To invoke *palliative care* is to call upon a newly recognized specialist practice that has evolved primarily for the care of persons with incurable cancer. It is a practice that embodies a philosophy of compassionate concern, one that recruits human and technical resources to provide a cooperating and comprehensive oversight and continuing support to relieve the totality of discomforts (physical, emotional and even spiritual).

Palliative management or the *practice of palliation* takes up the basic philosophy of palliative care, but brings it into fields other than cancer, encouraging the implementation of constructive palliation by any clinical speciality. Palliative management has been neglected in the modern emphasis on triumphs of cure or major disease modification, but it becomes the most appropriate approach to care when it is apparent that a patient's disease cannot be cured, or that the course of that disease cannot be modified in any significant way. The emphasis of professional attention is then on comfort and the maintenance of best possible function.

Palliative management will offer a comprehensive support that addresses the many components of discomfort (physical, emotional and spiritual) that may accompany advanced disease, and will make that support part of the responsibility of care. It will incorporate much of the approach to care that has developed within the speciality of palliative care, and sometimes it may work closely with staff from that speciality, but more often it will not. It will seek to allow the patient maximal opportunity to participate in decisions

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about what care is required, and where it is best delivered. It will recognize that no one professional can deliver the wide range of interventions that have potential to assist patient and family, and encourage the participation of a multi-disciplinary team equipped to assist care at any site, whether in acute hospital or aged care facility, in the home or in a specialist in-patient unit.

The origin of 'palliation' and 'palliative' is the Latin: *pallium* means a cloak. The term palliation began, it would seem, with the idea of covering over or keeping out a discomfort to make it bearable, as a cloak will hide a disfigurement or will prevent cold air chilling the body. It describes an action that seeks not to reverse the cause of a discomfort, but to shield against its effect; not to bring about a complete restoration or cure, but to provide a shelter within which to find a greater measure of coping and comfort and well-being.

'HOSPICE' AND PALLIATION IN ADVANCED CANCER

The word 'hospice' is commonly used in connection with palliative care, sometimes to indicate a building: '*St Christopher's Hospice*'; sometimes a group of workers: '*the hospice team*'; sometimes a programme: '*The Northern Hospice Service*'.

'Hospice' also has a Latin origin: *hospes*, meaning a guest, or a host who receives a guest. A 'hospice' was an important part of a typical European Monastery one thousand years ago, providing accommodation for travellers, but was also a place where the monks could offer care for sick or indigent persons.

The term 'hospice' was adopted in the modern era by pioneers such as Mary Aikenhead in Dublin, and Cicely Saunders in London for the institutions they established for the care of dying persons, and it became a common name for such places. It remains a favourite word for indicating a building where dying persons receive care, but for other uses it is now commonly replaced by 'palliative care' or 'supportive care'. In many places there are restrictions on the diseases regarded as suitable for referral to a hospice programme or admission to a hospice; for example, a diagnosis of advanced cancer and a prognosis of less than a defined duration (e.g. 6 months).

Palliative care continues to evolve, however, and is increasingly accepting responsibility for conditions other than cancer.

PALLIATIVE MANAGEMENT IN NEUROLOGY: AN INCREASINGLY RECOGNIZED NEED

In the practice of neurology, many degenerative conditions are not accessible to cure and cause major discomforts and much family distress. Many have the additional feature of a prolonged course that entails a heavy continuing burden on the family support and health services involved in care. In Japan, the term for these conditions translates appropriately as '*obstinate diseases*'. The speciality of neurology is a particularly appropriate setting for palliative management.

In the prolonged course of many '*obstinate diseases*' it may be possible to distinguish two phases, namely a supportive phase and a terminal phase. The separation of these phases will often be indistinct, however, and palliative interventions may have value in either:

- (i) In the '*supportive phase*' management will aim for maintenance of function at the best level, and the relief of discomfort will be directed to that end. This will involve palliative interventions that mitigate the effects of underlying pathology, and provide a temporary relief, allowing the affected person the best opportunity of continuing life as normally as possible. This phase is usually the responsibility of the neurologist and the family physician. For some particular interventions they may call upon the expertise of other specialties: surgery, speech therapy, psychiatry, etc.
- (ii) The '*terminal phase*' starts when it is clear that function is becoming severely impaired, and irreversible further changes are now being recognized which herald the approach of death. This is a time when more demanding personal care is likely to be required, when symptoms may be more difficult to control, when care by family members will need additional support, and the patient may require temporary or long-term admission to an in-patient setting. At this stage, if funding provisions allow and resources are available, palliative management may be enhanced by access to the skills, experience and resources of a multi-disciplinary palliative care service. Often, however, the neurology team or the family doctor and community agencies must accept the major responsibility for the delivery of care.

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DIFFERENT TRAJECTORIES OF CARE FOR CANCER AND NEUROLOGICAL DISEASE**Cancer**

A common diagram to indicate the timing of the relationship between oncology and palliative care in the management of cancer shows that the diagnosis of cancer and its initial treatments are within the province of the oncologist, who provides a continuing oversight as measures against the cancer (surgery, chemotherapy, radiotherapy and hormonal treatments) are undertaken (Figure 1.1.1).

The early weeks and months following a diagnosis of cancer are often times of optimism and hope, with (usually) some response to treatment. Prognosis, though still uncertain, seems open-ended. Some time later, however, if recurrence of the cancer becomes apparent, and chemotherapy is less effective, patients will be encouraged to accept the multi-disciplinary assistance of a palliative care team.

A palliative care team, by its name and reputation, represents the reality of approaching death, and referral to palliative care often is not easy for individuals and families to accept. Many will recognize, however, the palliative care team promises the patient a skilled and attentive support throughout the final phase of the illness. That support will be multi-dimensional, embracing symptom control, equipment provision, and concern for the emotional and spiritual well-being of the family as well as the patient. It will be offered on a continuing basis at whatever site of care the patient chooses as most appropriate, and will continue as bereavement support for the family, after death has occurred.

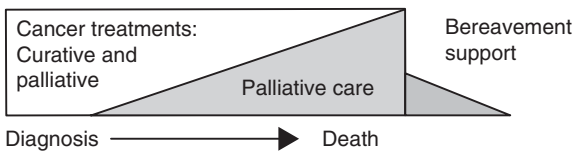


Figure 1.1.1 Relationship of oncology and palliative care.

Neurological diseases

'Obstinate' neurological conditions commonly have a much longer clinical course than is usual with advanced cancer, even though the eventual outcome may also be death. The themes of management in the early 'supportive' stage are those of encouragement, rehabilitation and preservation of function, as well as palliation of symptoms. Supervision is commonly by a

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neurologist, working within a team structure that includes other health care disciplines. In Figure 1.1.2, the trajectory of a typical degenerative condition is compared with that for advanced cancer and severe respiratory and cardiac diseases. A palliation approach becomes the appropriate response rather late in the course of many cancers, and is less consistently brought into the conduct of care for respiratory and cardiac diseases. For those, the final months and years may be marked by successive crises of acute deterioration, necessitating a series of acute hospital admission for active curative treatments with (hopefully) subsequent recovery after each, but a steady underlying decrease in function, until finally it becomes accepted that further intensive treatment is unlikely to be successful and may be very uncomfortable. Some incurable neurological conditions may follow a terminal pathway similar to cancer or to cardiac disease, with patients not feeling 'ill' until the condition is far advanced; but for other 'obstinate' neurological conditions such as dementia, amyotrophic lateral sclerosis (ALS) or multiple sclerosis (MS), from almost the time of diagnosis, palliation is a close partner with whatever treatments are undertaken to seek to modify the course of the illness.

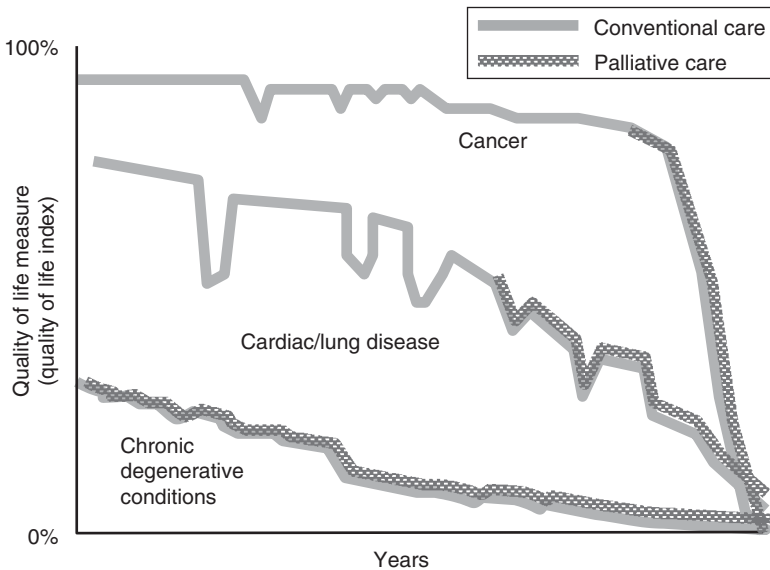


Figure 1.1.2 The pathway of conventional treatments and palliation in major terminal diseases.

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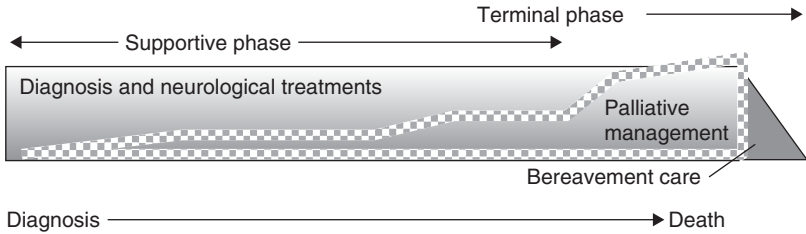


Figure 1.1.3 The relationship of supportive and palliation management phases.

Figure 1.1.3 returns to a comparison with Figure 1.1.1. The boundaries enclosing neurology and palliative management are drawn as less distinct than for oncology and palliative care. Expertise in palliative management will be useful early in the course of the illness, and becomes more and more necessary as the end approaches, when physical abilities are failing, cognition is more impaired, and comfort in all its dimensions becomes more difficult to maintain. The phases labelled 'supportive' and 'terminal' therefore overlap.

By accepting their major role in palliative management, neurologists stand to find new interest and confidence in the management of patients with chronic degenerative conditions. It may lead to a closer partnership with local palliative care teams, offering mutual advantage to both disciplines, and the opportunity for improved care for the many neurology patients who suffer from advanced and terminal disease.

PALLIATION AND NEUROSCIENCE

Around 100 years ago, major advances were made in the understanding of neurological function, as it became possible to assign specific functions to designated areas of the nervous system. Particular nerve tracts and particular collections of neurones in the brain were identified, and anatomy and function could begin to be correlated. This led to understandings of the progression of a stimulus such as pain from the periphery of the body (as with a bruised finger) ascending along nerve trunks, passing through synapses at various points but directed always centrally towards the thalamus and cerebrum where the experience of pain was appreciated, and localized to the site of the stimulus.

It was always clear that this was an inadequate over-simplification. New technologies such as positron emission tomography (PET) scan and

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functional magnetic resonance imaging (functional MRI) have now made it possible to visualize the simultaneous close interaction of the many elements of the nervous system. We can now recognize a far greater complexity of response to a pain stimulus, with multiple neuronal signals transmitting not only centrally along the recognized ascending tracts, but following descending pathways also, and reverberating within the brain and spinal cord:

'A complex barrage of multi-sensory afferent signaling arrives at the brain constantly, and this array varies from moment to moment. The signals from [the new stimulus] are relatively minor features of the stream of neural signals that reaches the brain, yet they affect consciousness, causing pain'.

*Chapman CR, Nakamura Y. Pain and consciousness.
Pain Forum 1999; 8:113–23.*

An old way of telling a lay person about the brain was to liken it to a telephone exchange, in which each part of the body had its messages directed to an appropriate part of the cerebrum, where it could be appreciated consciously, and from which responses could be directed and sent out.

A better model for brain function may be something quite chaotic in form (something more akin to a nest of ants in frantic motion), with messages running between all parts in all directions, yet somehow directed and arranged and organized to make sense: sense composed of various orders of complexity and sophistication, and sense that varies from time to time:

'Non-conscious and massively distributed central processes integrate the signals from nociceptors with other sensory and affective activity in the brain and various memories and associations'.

Ibid.

The patterns that form, moment by moment, in this swirling mass of activity are replaced immediately by others, but there is also potential to store meaningful patterns of activity in some way, making them available for recall or unconscious operation. They will recall past experiences and influences and also frame expectations for both the present and the future.

This modelling of the central nervous system has led to new concepts of consciousness, seeing it as a quality that the brain is constantly revising, elaborating new drafts of awareness, and constructing dynamic representations of reality. In our awareness, nothing is 'actual' or 'true'; it is a construct in which input from the five senses is much influenced by both memory and expectation.

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None of this bold reformulation of neurophysiology should be a surprise to practitioners of palliation. They know that the same apparent intensity of stimulus will result in quite different responses in different individuals or in the one person at different times. The ‘holistic’ approach to palliation that its representatives advocate is one that seeks to maintain, for a suffering individual, an interest in the total context of discomfort, the past experiences, the family connections, the anxieties and fears that affect him, the meanings he is able to give to the current experience. Clinicians try to tune into elements of that person’s neural complexity, to appreciate and influence the patterns that are recurring within that nervous system and are causing discomfort. This is no simple task, and it is presumptuous to expect success in bringing comfort. But that is the task, to be undertaken in humility, and as conscientiously as possible.

Compassionate palliative management seeks a close and intimate awareness of a suffering individual’s situation. In exploring the potential elements that contribute to that suffering, those who profess palliative management bring their own neural complexities into apposition with those of the patient (utilizing both rigorous clinical assessment and intuition), hoping to *feel* the content of that individual’s discomfort, and at the same time measure it in some scientifically acceptable way. It will be good if the caring physician, drawing on available scientific evidence, is, at the same time, aware of the influence of his or her own personality, history and current situation, personal memories and patterns of neural activity, since these clearly affect the perception of the patient’s problems.

Sometimes there is little for the physician to offer apart from presence and personality:

‘One thing I have learned is that the best thing that anyone can do for the dying (or bereaved) individual is to show that you care. ... You don’t even have to mention the problem at hand, just show the person that you are thinking about them and therefore are helping to shoulder their burden. As neurologists ... we are obviously providing a lot of comfort for our patients just by seeing and talking to them, even in hopeless cases.’

Spoken by distinguished neurologist Philip Geoffrey McManis in the final weeks of his life, prior to his death from oesophageal cancer.

Quoted in McManis’ obituary by C. Michel Harper. Neurology 2005; 64:598–9.

External stimuli from many sources also have the potential to be recruited and incorporated in a neural pattern arising from some trauma or pathology, and they can strongly influence the degree to which there is pain or other

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distress. Fear and anxiety, past distress, an uncomfortable isolated environment or loneliness are all human experiences that can augment suffering, and probably have their effect through modifying neural patterns. Similarly, stimuli of a potentially pleasant nature, such as familiar and meaningful music, touch, massage or attractive odours, the various components of complementary therapy, may become incorporated into complex neural networks and alter them in ways that reduce discomfort. There is already evidence that the neural patterns evoked by pleasing music differ from those evoked by music that is not welcomed. Complementary therapies have the potential to modify neural patterns such as are evoked by pain.

Amazing scientific advances have ensued from active pursuit of analytical methods, but now we have to encourage them to fit into a broader approach to diagnosis and therapy. Palliation, in particular, while it draws enthusiastically on evidence-based medicine, must accept rigorously won evidence as only one component of many that contribute to clinical understanding of the whole of the suffering experienced by an individual.

Palliation in an age of new, more successful therapies

Promising results are being reported for the use of embryonic and adult stem cells for neuro-transplantation in animal models of diseases such as Parkinson's disease. The view that neuronal tissue is immutable is being modified, replacement of nerve cells occurs in specific areas such as the dentate nucleus and the sub-ventricular zone of the lateral ventricles. Response to brain injury by an increase in nerve cell production and regenerative repair has only recently been recognized. Stem cells can invade the cord when introduced into the cerebrospinal fluid (CSF) in rats. Reports from China of symptom improvement in patients with ALS, MS and Parkinson's disease following introduction into the brain of olfactory ensheathing glial (OEG) cells from foetal olfactory bulb tissue are also encouraging.

Many issues remain to be elucidated, but there is a new excitement in neurology as it views the prospect of many new techniques with potential to reverse some hitherto incurable pathologies of the nervous system. That prospect in no way diminishes the need to offer effective palliation.

This small book will have achieved a major aim if it encourages a closer collaboration between scientific neurology, with its confident exploration of new developments in effective treatment, and palliative management, with its comprehensive attention to discomfort. A bi-partisan effort in care offers a brighter horizon of hope for patients afflicted by chronic degenerative disorders of the nervous system.