

Review

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Abstract

The majority of Australians with life-limiting illnesses are cared for at home by their families and friends with medical support provided by their General Practitioner. A large number receive additional care from Community Nurses who are usually based in specific Palliative Care services. Several agencies provide home help, performing services such as cleaning, laundry or shopping, and these can sometimes be paid for or contributed to by the government. In Nepal well organized palliative care services are not available. Palliative care is provided by primary physicians/ surgeons indicating a shortage of specialists in the field, in addition many doctors and health services providers do not regard palliative care as a priority. In Nepal most patients live in remote rural areas of the Himalayas. In both Australia and Nepal the patient can spend the last few days at home. However the government in Australia is able to provide much more support to families in these circumstances, in Nepal families must be very much more self sufficient. The views expressed in this article are those of the authors and do not reflect any official policy or practice.

Nepal

Nepal has 24.2 million inhabitants (estimate 2003) with 14 % of the population living in urban and 86% in rural areas.Per capita income is only US\$220, half the population lives on less than US\$1 per day. 38% of the population lives below the poverty line. Illiteracy is very high, with around 40% of men and 75% of women unable to read or write. Overall health indicators are poor and differ significantly by region. Life expectancy at birth (year, 2003) is 60 yrs for males and 61 years for females.Health expenditure is US \$ 11.2 per head (5.3% of GDP).¹ Government input is about 16% of total health expenditure.NGO contributes to about 15% of total health expenditure; in addition there is no health insurance system. In Nepal well organized palliative care services are not available. Palliative care is provided by primary physicians/ surgeons indicating a shortage of specialists in the field, in addition many doctors and health services providers do not regard palliative care as a priority. Palliative health care services are mainly concentrated in and around Kathmandu, the Capital city with only about 50 in-patient beds available. INTCR has been active in this field in Nepal since 2004.²



Australia

The majority of Australians with life-limiting illnesses are cared for at home by their families and friends with medical support provided by their General Practitioner. A large number receive additional care from Community Nurses who are usually based in specific Palliative Care services. The organization and structure of those services vary in different parts of the country but in most large centres include Palliative Care Doctors, Counsellors, Pastoral Care Workers, Social Workers , Volunteers and sometimes other allied health professionals such as Occupational Therapists, Pharmacists, Dieticians , Physiotherapists .

A smaller number of patients will spend their last weeks in Aged Care homes, Hospices or Private or Public Hospitals. Each specialist Palliative Care Service, whether it is Hospital, Hospice or Community based, works within Palliative Care Australia's national standards which in turn reflect the World Health Organization's definition of Palliative Care:



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"Palliative care

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten or postpone death;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the patients illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- will enhance quality of life, and may also positively influence the course of illness;
- Is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications."

(http://www.who.int/cancer/palliative/en/)

Unless a patient chooses to see a private specialist, or be admitted to a private facility, palliative care services are almost entirely free to the patient, being funded by State and/or Federal governments.

Unfortunately, from a General Practitioner's perspective, patients requiring palliative care are amongst those patients most likely to need home visits, lengthy discussions with relatives or caregivers and "non-contact" services such as telephone prescriptions or discussions with community nurses. These services are generally poorly funded or entirely unfunded by the government. There is a natural reluctance to charge terminally ill patients for such services. This leads to some General Practitioners being reluctant to provide palliative care for their patients and on occasion to some difficulties between GPs, community health nurses and palliative care services.

A 70 year old male patient who received surgery for prostate cancer last year. He presented with back pain (T-spine) and received radiation therapy for metastatic disease six months ago. He has now presented complaining of a painful left shoulder. The pain is concentrated between the shoulder joint and the scapula. The pain is worse in bed at night. He has limited movement and walks into the clinic clearly in pain. The pain commenced recently and does not relate to an injury. He has previously not had shoulder pain. He is not experiencing any pain elsewhere. What is your approach to this case?



Patient should be advised regarding sling support to rest the shoulder joint. Surgical option available would be joint replacement with prosthesis but such a procedure would be unlikely done here.



It is very likely that this patient's pain is caused by bony metastasis. In most areas of Australia a plain X-ray would be able to be arranged on the day of consultation to confirm this. If the X-ray were normal a bone scan could be performed. Given that radiotherapy has been so successful for his previous bony metastatic disease it is likely also to be effective for his current symptoms and a referral would be made (usually by phone) to the radiation oncologist. There is very likely to be a delay both before the patient receives his radiotherapy and also before his pain responds to that treatment. Furthermore, there is often exacerbation of pain immediately following radiotherapy (pain flare). Therefore, pharmacological management would also be initiated. This would usually consist of opioid analgesia (initiation of, or an increase in dose if the patient is already on an opioid). Initially dose titration, using short-acting formulations of drugs such as morphine or oxycodone, is usual, with conversion to longer-acting preparations once the effective dose is established. Short-acting formulations may continue to be needed for "breakthrough "pain. A corticosteroid (e.g. dexamethasone) or non-steroidal anti-inflammatory drug and/or paracetamol may provide additional analgesia if the pain is not fully controlled. A trial of dose-reduction or cessation of analgesics may be possible 2-4 weeks following effective radiotherapy. Non-pharmacological management may include immobilisation with a sling, transcutaneous electrical nerve stimulation (TENS), heat packs, cold packs or acupuncture.

Palliative treatment with specific antitumour therapy may be appropriate. These include hormone ablation therapy (e.g. Zoladex/Lucrin or Androcur) or chemotherapy. Review by a medical oncologist or urologist would be required for these options to be further discussed with the patient.





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40 year old single male with widespread recurrent bladder cancer and bony metastases. He presents with haematuria. Patient has normal renal and liver function. He refuses to have surgery. What options are available to help this patient?



In a patient with recurrent bladder tumor that has earlier not been radiated in which surgery is not feasible or not acceptable by the patient, concurrent Chemoradiotherapy following maximal possible resection of the tumor via a trans-urethral approach is advisable. Also in the same sitting all the weight bearing areas of the bone which has active metastatic disease as seen on an X-ray can also receive palliative radiotherapy with or without bisphosphonates like zoledronic acid on 3-4 weekly basis. The treatment usually comprises of 45-50 Gray of radiotherapy to the entire bladder with or without the pelvic nodes followed by a boost to the gross tumor site till 60-66 Grays over a period of 6-7 weeks. An initial haemostatic dose of radiation (400 cGY) can be given for the initial one or two fractions to control the bleeding. Concurrent Cisplatin with or without 5-Flurouracil can be given either on a 3 weekly or weekly basis depending upon the general condition of the patient. In those cases where general condition doesn't permits chemotherapy administration, only radiation can also be given. In patients who have received radiation before and now presents with recurrence, palliative chemotherapy with Cisplatin and Gemcitabine can be employed on a 3 weekly cycle basis for about 6 cycles. Use of haemostatics, blood transfusions may be warranted in cases with frank hematuria.



Treatment in this case would depend upon the degree of haematuria.

If the patient is on an anticoagulant or platelet aggregation inhibitor then consideration could be given to ceasing these. If the haematuria is minor and the patient otherwise asymptomatic then there is no absolute need for treatment at this time.

For more significant haematuria, radiotherapy may be of benefit if the patient is willing to undertake this. If clot retention is causing symptoms then a large bore catheter can be inserted and intermittent or continuous bladder washout with saline commenced. Pain from clot retention is often refractory to all forms of analgesia and management with catheterization and bladder irrigation is essential. Intermittent treatment with an opioid may be required (e.g. immediate release morphine or oxycodone, Fentanyl citrate lozenges). Oral tranexamic acid is sometimes used, but can cause increased formation of firm clots that can be difficult to remove.

A young man with good performance status and normal renal function would probably benefit from combination

chemo-radiotherapy for symptom management and life prolongation and a referral to an oncology or urology specialist would thus also be made if appropriate.

A 65 year old man presents with severe vomiting associated with bowel obstruction and ascites. He has been diagnosed as having colorectal carcinoma with multiple metastases. He refuses hospital treatment. What are your options?



Such a patient can be managed with placement of Nasogastric tube to aid in decompression of the abdomen. Antiemetics like 5HT-3 antagonists like ondansteron with an initial tapping of the ascitic fluid with adequate fluid replacement therapy. Patient can be prescribed on pain killers if required but with caution as they themselves can cause vomiting. He would require home based palliative care by a resident home nurse but since such an approach is rarely available in this part of the world he would probably have to visit the nearest health care centre from time to time for repeated taping of the ascitic fluid with fluid replacement therapy.



Treatment in this instance would be symptomatic, with analgesics, antiemetic and anticholinergic medications being the mainstay of treatment.

For antiemetic, prokinetic medication (e.g. metoclopramide via a continuous subcutaneous infusion) would probably be tried initially, unless a complete mechanical bowel obstruction is suspected (unlikely in this case). If pro kinetic agents were ineffective, haloperidol, prochlorperazine, or cyclizine could be used. Parenteral administration (intramuscular or subcutaneous) would again be necessary initially, until vomiting subsides. Analgesia would be initiated or continued with opioid analgesics (morphine or hydromorphone are suitable for parenteral administration and could be combined with an anti-emetic in a subcutaneous pump if required). Transdermal durogesic would be another alternative. Anticholinergic drugs e.g. hyoscine would be given to reduce intestinal secretions, to reduce colic and for its antiemetic effects. Octeotride could also be tried, its effect on reducing gastrointestinal secretions and motility sometimes reducing nausea and vomiting. Corticosteroids (usually dexamethasone) would be initiated to assist in resolving the obstruction.

Non-pharmacological measures include the treatment and prevention of constipation, and the reintroduction of oral fluid and food in small amounts as the obstruction resolves.

In this patient, the bowel obstruction is quite likely to be incomplete & to resolve with conservative therapy, & a trial of this approach would be offered to the patient even if he WERE willing to consider nasogastric drainage and IV fluids or surgical management in hospital.

Abdominal paracentesis might be appropriate and



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sometimes can be performed in the home. Drainage of ascites can be an effective remedy for ileus.

Patient has recently been diagnosed with advanced lung cancer, but is reluctant to have chemotherapy or surgery because is worried about side effects. Patient recently started complaining of headaches and was referred for a CT of his head. Diagnostic CT report demonstrates a single cerebral lesion in the frontal lobe. He also wonders what other treatments could be provided for his headaches, but he is worried about side effects. He does not want surgery. What options are available to you?



Apart from symptomatic management of brain metastasis with mannitol and steroids and anti-convulsants a solitary brain metastasis should be ideally managed with surgery but in this case as the patient refuses surgery , he can be treated with whole brain radiotherapy comprising of 30 Gray of dose given over 2 weeks of time. A solitary small brain metastasis can also be dealt with stereotactic radiosurgery/radiotherapy (SRS/SRT); however such a facility is not available in Nepal.



In discussing the therapeutic options with this patient and his family/caregivers, it would initially be important to reexplore the patient's decision to decline chemotherapy or surgery, to ensure that this was made with a full awareness of the possible benefits, risks, side-effects and management options for those side-effects. Assuming that his decision in this regard remains unaltered, referral for radiotherapy for the (presumed) cerebral metastatic disease could be offered. If this were declined, and/ or in the interim, corticosteroids (usually dexamethasone) would be suggested. As this patient is clearly concerned about possible side effects, these should be explained in whatever detail he wishes. However it would be important to explain that the chances of symptomatic benefit for his headache (in the order of 80%) would greatly exceed the chances of a clinically significant adverse effect (in practice insomnia, oropharyngeal candidiasis or proximal muscle weakness would be the least unlikely side-effects). Following neurological improvement the dose of steroids would be tapered to the lowest effective dose. Corticosteroids would also lower the risk of side-effects from radiotherapy should the patient choose to proceed with this treatment option.

Should he decline corticosteroids or if these were incompletely effective, analgesic options (paracetamol, non-steroidal anti-inflammatory, or, most likely, opioid analgesics) would be offered together with a discussion of their possible adverse effects.

In the absence of seizures, prophylactic anticonvulsant medications would not usually be offered. However the risk of a convulsion should be explained to the patient and caregiver, together with a discussion regarding immediate management of these potentially frightening events. Caregivers are sometimes greatly reassured by having a supply of clonazepam drops to administer to the patient should a seizure occur. The cerebral metastatic disease may result in impairment of cognitive function or mood, anxiety or agitation, personality change or sleep disturbance delirium. Appropriate explanation, psychological support for patient, family and caregivers and, if necessary, neuroleptics, sedatives/anxiolytics, or antidepressants would be offered. The patient would be advised that he should not drive.

A 78 year old man has been diagnosed with metastatic lung cancer. He is cared for by his elderly wife at home. He is incontinent and confused. His wife does not want him admitted to hospital but is struggling to look after him on her own. What support is available to help care for this patient at home?

As stated earlier home based palliative care is rarely available in Nepal as most of the patients come from remote rural areas of the Himalayas. This patient can probably be catheterised with either a Foley's catheter or a lesser invasive condom catheter. Patient's wife can be advised regarding adequate salt in his diet along with other nutritional support.



From the medical perspective, it would first be important to try to establish the cause(s) of the patient's confusion and incontinence. There may be a reversible cause (for example hypercalcaemia, Urinary Tract Infection or latrogenic) the treatment of which may completely resolve his symptoms. Alternatively there may be a cause which may not be curable but the knowledge of which may alter management decisions (for example cerebral metastases).

Whilst specific causes are being investigated and addressed by the patient's GP, palliative care doctor and/or oncologist, or once all potentially reversible causes have been excluded, delirium treatment would be initiated and is likely to include a combination of neuroleptics (haloperidol) and sedatives (lorazepam or clonazepam).

The support services available to the patient's wife to assist with caring for him will depend to some degree upon whereabouts in Australia the patient lives.

Most regions in Australia have a palliative care service which would include community health nurses or remote area health nurses to assist with nursing care, including perhaps supply of urodomes or catheterisation if appropriate.

Most services also offer one or more of counsellor, pastoral care worker, social worker and volunteers to assist with both practical and psychological support. Many also stock and supply physical aids such as commodes, hospital-type beds etc.



Personal care services to assist with daily living activities such as toileting or showering are available in almost all areas, and can be government or self -funded depending on individual circumstances. Several agencies provide home help, performing services such as cleaning, clothes washing or shopping, and again these can sometimes be paid for or contributed to by the government. If the patient is an ex-serviceman, .these and other required services can be funded by the Department of Veterans' Affairs. If desired, a period of "respite care" in the home, a hospice or aged-care home may be available.

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PEER REVIEW

Commissioned; not externally peer reviewed

CONFLICTS OF INTEREST

None