



THE PRACTITIONER LE PRATICIEN

The occasional palliative care patient: lessons we have learned

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Palliative care is an ideal and creative part of rural general practice. It's an opportunity for deepening relationships with families and patients, and a healthy challenge for our medical skills.

Rural physicians are used to being "Jacks of all Trades." Palliative care falls within our role of treating patients throughout their life cycle. As with other neglected areas of clinical care, palliative care is the focus of extra training initiatives. Extra training is fine for those who take the courses, but it shouldn't send the message that it's a skill beyond the scope of all rural physicians called upon to help their patients die comfortably, often in their own homes.

For ease of reading, we will refer to the patient as "he."

THE PATIENT (Box 1)

A palliative care patient usually comes to us with a terminal diagnosis; but sometimes we're the ones to give the news. Either way, the art and science of palliative care begins after the patient is informed. Denial is a powerful coping mechanism, and it is not our role to disallow it. Although Kübler-Ross¹ described 5 stages of dying, the process

is an intensely individual one and doesn't always travel the same route.

The patient may have been told, yet may seem to not understand. This sometimes requires re-explaining, but sometimes not. There are times when he has all the knowledge he needs but, emotionally, it's too much to digest. In this scenario, we simply ask if he has any questions. Over time, he may ask about his prognosis, but he may not. A qualitative study discovered that patients want us to give them information only when they ask for it. They often felt information was being forced on them.²

Patients who were clearly going to die soon have asked for more treatment (e.g., chemotherapy), and we've struggled between "informing" them again or leaving them in denial. We've handled this by saying they'll get more therapy if they are well enough for it. Attending family members are told the appropriate facts, and that the patient has been given the same information but is dealing with it in a very different manner.

The patient and family may move from denial to acceptance,¹ but not necessarily. Our job is to find common ground. This may be different for the patient than for his family. Dying patients set the agenda through which we deal with them. We'll likely have a more directional role with the family, ensuring they have a realistic view and time to prepare for the inevitable.

Patients may want to discuss future symptoms, sometimes only present concerns. When they ask a question they're telling us they're ready for an honest answer. There's a wide range of

Box 1. The patient

- Pain versus Confusion is the simple equation.
- May want to remain in denial of diagnosis, and that's okay.
- May want to "know" very little, once already informed.
- Patient's wishes win out over family need for more therapy or treatment.
- End most sessions by asking if there are any questions.

topics: pain, bleeding, privacy, control, dying, the afterlife. When discussing with the patient the overall approach he prefers, we generally ask how he'd like to handle the balance between pain and confusion. This is a fluid course, and patients will tell us when they want comfort above all other considerations.³ This may not occur until symptoms worsen and the family have gathered.

THE PHYSICIAN (Box 2)

Rural physicians have one advantage over their urban counterparts: no traffic. House calls and home deaths are more feasible to attend. It's often good to involve a second physician if the care is onerous or will be prolonged, especially when house calls need to be done twice a day.

Box 2. The physician
• Role model a non-intervention style of care. • Allow for a sense of humour. • Consider involving a second MD, where required. • Focus on where the patient is at; the vibe.

We're the model for calmness for the other caregivers and the family. We must accept that this patient's dying is a part of his life and that caring for him is an important part of our job. We need to normalize the loss of function and consciousness he will experience.

Anuria and Kussmaul-Kien respiration is normal for a dying patient. We should have an almost "welcoming" attitude toward whatever direction his condition takes. It is all okay, except for pain and distress — those symptoms we must medicate. Dyspnea and pain usually respond to narcotic administration.

DO NOT PROLONG DYING (Box 3)

Do not prolong dying if you can avoid it. However, patients sometimes have a visitor they're waiting for, or an upcoming special event. Otherwise, IV hydration just prolongs the dying process and exhausts the patient and the caregivers.⁴⁻⁶ The use of oxygen therapy and bloodwork makes home deaths less feasible in many areas and adds little in the way of comfort for patients.^{7,8}

Box 3. Do not prolong dying
• No intravenous • No bloodwork • No oxygen
These are not comfort measures.

If a patient has been transferred from a tertiary care centre and is still receiving IV hydration and oxygen, the family will often resist the removal of these modalities. Try to get them to agree that the IV will not be restarted if it comes out, because it would be unfair to the patient. Often the best that can be done in this situation is to decrease the IV to a minimal flow rate.

If the transferred patient is not receiving hydration, expect someone in the family to ask why. We usually tell them that it would prolong the dying process and, again, is not fair to the patient.

THE FAMILY (Box 4)

The family may take out their stress on one another or on caregivers, including the physician. Expect some dysfunction. Attempt to work closely with just one spokesperson. This is often the hardest part.^{9,10} Try to 1) develop a communication strategy; 2) outline the patient's wishes and how you intend to fulfill them; and 3) recognize that family members are often also a part of your rural practice and they'll need time for their own needs to be met as well.

Box 4. The family
• Expect some conflict. • Try to stay out of it. • Discuss opportunity for some reminiscing, joy. • Stay firm once non-treatment is accepted by patient. • First priority is to patient wishes and comfort. • Family is often fearful of physical manifestation of death. • Non-intervention care may seem like poor care to family. • They may need reassurance that nothing urgent needs to be done.

Family caregivers may have a wide interpretation of physical symptoms, and they often need reassurance.¹¹ They may fear dramatic events such as major hemorrhage or a seizure. Explain that these are unlikely and that any symptom development is okay, as long as the patient is not in pain or distress.

Stressed families often "scare" away caregivers. The nurses may not want to disturb a close family gathering, but the family may see this well-meaning action as neglect. Therefore, it's important to persevere and for the family to understand that routine comfort and nursing care has to be given.

It's difficult to navigate the change from active care to comfort care for many families. Try to take the perspective that there's nothing that can be done to stop the disease, and it's our role to maintain comfort.

When family members who live farther away finally arrive, they are often out of synch with

where in the dying process their loved one is and with the decisions that have been made. This disadvantage may translate into suggestions to “do more” — almost a lobbying effort for increased intervention to assuage any guilt for not being there sooner. Our role is to listen, but to remain firmly committed to comfort measures for the patient and an acceptance of the dying process.

ABORIGINAL FAMILIES (Box 5)

Aboriginal families present more facets to the care of a dying patient.¹² There are areas of meaning for the patient and family that non-Aboriginal physicians may not understand.¹³ Often, several spokespersons are involved, which requires repeat discussions.

Box 5. Aboriginal families

- Difficult for non-Aboriginal MD to fully understand.
- Be consistent that comfort measures will not cause death.
- Loss of patient may have far-reaching past and present meaning for family.

These families may have preferences about when the body should be moved, and that must be discussed with the funeral home. Often the death of an elder will bring many visitors, and this should be anticipated and planned for ahead of time.

There may be many phone calls from distant communities, and a workable communication strategy that balances patient confidentiality and community information should be worked out.

MEDICATION (Box 6)

Medications can be legion, yet need not be. Keep it simple. When the patient can no longer swallow effectively, morphine, administered subcutaneously, will manage most pain and shortness of breath.^{8,14} Train family members to administer morphine injections and have them do one while you are present (see Appendix 1). Setting up a simple schedule can make the caregivers at ease with this new task. Dose and volume can be increased as required. Prime the butterfly tubing with morphine and do not flush; that way the patient is always getting a reasonably predictable dose. Increase doses by 50% when inadequate. There is no upper limit. Start early because catch-up is hard to play.

There is nothing more distressing to caregivers and family members than a distraught, thrashing, dying patient. This patient needs to be urgently and aggressively medicated. Intramuscular (IM) injections of phenobarbital, diazepam and haloperidol every half hour until the patient settles are very

Box 6. Medication

- Subcutaneous morphine site usually suffices.
- Do not flush; keep primed with morphine.
- Teach family members to do injections.
- Reassure them they will not kill the patient with this medication.
- When deep sedation for agitated, dying patient is required: phenobarbital 300 mg + diazepam 20 mg + haloperidol 5 mg intramuscularly; Q hourly until sedated, then qid prn.
- Scopolamine 0.6 mg subcutaneously useful for “death rattle.”

effective. Use medications that work on divergent pharmacological pathways because it’s never clear which pathways may be shut down.¹⁵ This may also be a time to decrease narcotics. In the patient with failing kidneys, narcotics can cause delirium.

The “death rattle” is difficult for caregivers to listen to, and is effectively managed with scopolamine (0.6 mg), administered subcutaneously. This dries up upper airway secretions; it may need to be repeated prn.¹⁶

NURSING AND HOME CARE (Box 7)

Nurses are the main caregivers in the hospital setting, just as family and friends are in the home setting. The physician and nurses often need to troubleshoot issues together before the physician goes in to see the patient and family.

Box 7. Nursing and home care support services

- Often limited resources.
- Very important for comfort, bathing, nursing care.
- Ensure they are aware of your non-intervention approach.
- Incontinence brings many patients into hospital; strategize.
- Modest constipation: fleet enemas, better than incontinence
- Bedside commodes and Foleys are invaluable when needed.
- Get family to step outside room when regular care is required.

Nurses are key players and, as such, bear much of the brunt if the family is very stressed about the palliation of their loved one. They need our understanding and support when issues arise, and after the patient has died. They are often far more in tune with where the patient is “at” than the visiting physician is, and, in an extended-care unit scenario, they may have known the patient for years.

Do not underestimate the effect the death of a patient may have on the home support personnel and on the nursing staff. Nurses and family caregivers need to know that the patient is expected to

die. They should also be prepared for the fact that the death may occur after one of their medication administrations, and that this is okay.¹⁷

SUMMARY (Box 8)

Palliative care is a routine, creative and important part of rural practice, well suited to practitioners who are used to finding practical solutions for their patients' care. A simple, clear approach may be effective for the physician, the patient and his family.

Box 8. Summary

- Less is more.
- Comfort of patient is focus.
- Appropriate sense of humour.
- Model peacefulness and acceptance.

The bottom line is that we are not interfering with the dying process. We are keeping the patient comfortable. If the patient is "meant" to get better, nothing we do is standing in their way. We are doing nothing to end their life; their illness is doing that.

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Appendix 1. Administering morphine injections

1. 25-gauge butterfly needle, opsite dressing, injection site lock (Fig. 1).
2. Fill a butterfly needle with morphine, do not flush with anything (Fig. 2).
3. Place site on upper chest for easy access (Fig. 3).
4. Needle in place.
5. Cover with transparent dressing.
6. Dressing in place.
7. Leave prepared syringes for caregivers to administer prn (often useful to demonstrate the first dose) (Fig. 4.).

Photos by Dr. Yogi Sehgal.

