

Inquiry into health outcomes and access to health and hospital services in rural, regional and remote New South Wales

Supplementary questions for Dr Simon Holliday.

Comments re current palliative care provision in Taree and the region.

Comments on ways to improve palliative care provision in Taree and the region.

Hospital-based care

Prior to the appointment of Dr Arron Veltre as part-time palliative care staff specialist for Manning Hospital earlier in 2021, as I understand it, hospital based palliative care was run by the physicians. These specialists are trained in the diagnosis and treatment of illnesses. Their usual model of care generally involves active treatment ie "doing things." This is the opposite of that in palliative care where the role of the health care workers, usually, is to minimise symptoms and assist the individual and their near-ones through the end-of-life stages. This is not to say that palliative care is always reactive or passive as active treatment may continue in parallel for some aspects of the patient's condition. Relying on physicians for palliative care seems to be an extra unnecessary imposition on them, especially when alternatives may be more apt.

Where I worked prior to coming to the Manning, I always looked after the palliative care of my patients wherever they were, unless they needed to be transferred to a tertiary hospital or closer to their family. In the Manning Hospital, GPs rarely provide inpatient care. This is because the hospital has chosen to restrict GP-proceduralists. It is also because the remuneration is different to that found in Gloucester and other District Hospitals that utilise the rates negotiated with the NSW RDN. When I first came to the area, I continued my habit of regularly visiting my in-patients. However, I quickly abandoned this as the remuneration was poor, my patients who were admitted via ED went under specialists, and the nursing staff tended to invite the specialists to become involved which then sidelined me.

RACF-based care

In Taree, the GPs tend to manage palliative care in the Residential Aged Care Facilities (RACFs). Here some of the issues identified in the Royal Commission may emerge. Many management

decisions are made on commercial grounds rather than on a basis of quality of care. RACFs rely on minimum staffing levels and even then, rely on staff with the lowest pay-scale and so the lowest level of training and remuneration. Nurses low pay rates are made less unattractive by the tax concessions given to charitable or church-related organisations. Recruiting and retaining staff is difficult, as the pressure is constant and stressful, with nurses often sourced from locum agencies.

Accreditation seems to be the top priority for management. Nursing care becomes preferentially provided where it will complete the documentation to be audited at accreditation. Over my three decades of rural practice, GPs increasingly have opted out of RACFs. The pay is invariably bulk-billed and poor. GPs receive a constant stream of script requests from chemists, who often find it simpler, and more profitable, to request a new script rather than search for one already prepared. Families often feel in the dark, and so increasingly request to meet with the GP or have the GP phone them. The nursing staff seem to be instructed to inform the GP about every trivial matter and to request a review. An example of this may be where someone has slipped off a chair without any harm being done. After leaving the surgery at 7pm, at one recent visit, I asked the staff if they had set up 'fart charts' to enthrall me, such was the frequency and triviality of their calls.

Another development I have observed regarding palliative care in RACFs and less well-trained nursing staff is that they all assume no-one should die without a syringe driver. This is where a regular dose of morphine is injected under the skin by a pump. Comments by nursing staff to families can cause alarm. Families may stress because they believe that a syringe driver is critically important for all end-of-life care, even though the resident may be alert and able to manage both oral intake and analgesics. Use of a syringe driver unnecessarily forces technology into the family vigil. The frequent alarms on the pump tend to worry families.

The use of Clinical Nurse Practitioners (CNPs) adds another layer of care and command. They can bill the MBS directly. However, if a GP sees the patient on the same day the CNP did, the CNP cannot claim a fee. This is a potential conflict of interest. Several years ago, I was scolded by the CNP for attending an arranged family end-of-life conference on a day where the she had billed for her services.

All this is to preface my comments on palliative care provision in RACFs. I think the health services can do palliative care very well there. It could further improve if nursing staff were better trained, if there were more staff to patients, especially end-of-life care patients and finally GPs were better remunerated for the work whether in the RACF or to cover phone calls, faxes, emails and script requests.

Home-based care

GPs manage many of their patient's end-of-life in their own homes. Sometimes people may be transferred for the final days due to the physical burden of round-the-clock care. Most GPs would bulk-bill for this, as they know the patients well and can vary the timing of visits according to their schedules. However, at times when I have had to travel long distances each-way I have routinely charged a private fee.

The community health palliative care nursing team does a great job, although they are not available round the clock. They also tend to have a low threshold before contacting a Palliative Care physician directly. This can make the GP feel sidelined.

There is a lot of confusion on how to access packages targeting palliative care. Waiting times may have blown out or services may be too fragmented inaccessible, particularly the Federal "My Aged Care". During this distressing time, the complex procedures may confuse the dying patient and their family who may struggle to make decisions without much support or clear information. In the ACAT program, for example, there are multiple programs which each require an assessment, but no one supports the person being assessed to make the various decisions. A common scenario sees a person who was diagnosed with terminal cancer in hospital and requests their end-of-life care to be at home. They are referred via "My Aged Care" to the Aged Care Assessment Team (ACAT) to be assessed for services. There is a long waiting list for this and, sadly, many die waiting for the assessment or those necessary services. While waiting for a package that may never eventuate, many of these palliative care patients may be transferred to a RACF for respite. Younger patients cannot access the ACAT at all and so may lack the access to any packages as well as the backstop of an aged care facility.

Perhaps GPs could be supported to make the assessment process more timely and to coordinate and guide the other stakeholders.

Substance misusers and palliative care

This group have complicated needs and do not fit into the usual care paradigm. Such patients tend to be younger and chaotic. They often have precarious or dysfunctional social networks. In RACFs, those on methadone programmes during end-of-life face particular problems. Some pharmacies who hold the contract to provide services to an RACF do not (or will not) provide methadone or buprenorphine treatment programmes. I have had to arrange other pharmacies to come in to supply the treatment for just one patient. Also, the nursing staff are clearly uncomfortable with patients on drug treatment programmes, especially when there are challenging behaviours.

Those on drug treatment programmes rarely have a regular GP. Therefore, they do not have access to a GP for end-of-life care. As an addiction specialist I have had to undertake all the home-based care to navigate the care of an opioid treatment programme patient dying at home. There are no MBS Item numbers for home visiting by Addiction Physicians!

Final comments

As a long-standing rural GP, I have found providing palliative care one of the most rewarding parts of my role. It was a jolt to be excluded from the end-of-life care provided in hospitals when I came to the Manning. Every NSW rural hospital cannot rely on palliative care physicians and it seems unnecessary to burden over-stretched rural physicians with this care. NSW Health should look at supporting GPs to return to hospitals to provide inpatient care, for palliative care and potentially for other areas.

In RACFs, to improve care, we need to improve staffing ratios, support palliative care training for the staff and support GPs to provide care there.

In the community, we need to look at barriers to accessing the ACAT service as well as specific cancer care packages. Younger people and substance users deserve quality end-of-life care also, but too often are unable to engage with for the usual systems of care.

All these pressures have only been magnified by the fear and distance generated during the current pandemic.

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