Models of Care for Rural Palliative Care Services

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INTRODUCTION

Provision of care to patients with terminal illness has changed dramatically in all developed countries over the past 30 years. The thrust for this development arose from dissatisfaction by both patients and some health care staff with the care provided for dying patients in the existing health care system\(^1\). Symptom control was often inadequate, spiritual concerns not considered, fears and anxieties unrecognised, and needs of families not included in care planning. In response to this dissatisfaction arose the early hospice movement, which developed different models of care and a different philosophy. Three decades of maturation have seen those ideals evolve into modern palliative care, a specialised area of health care in which the essential role of interdisciplinary team-based care is undisputed.

Rural GPs have always had a central role in the management of their dying patients, and in the light of the increasing incidence of cancer in our ageing population, and improving societal acceptance of palliative care, this is likely to be increasingly so in the future\(^2\). Rural primary care medical providers have readily adopted improvements in the practice of palliative medicine, particularly with regard symptom control such as application of new-found analgesic regimens. Their approach as family doctors has traditionally involved holistic care of their patients with due consideration of family members and psychosocial issues as well as the biophysical. In many areas rural practitioners continue their responsibility for the patient into inpatient and residential care facilities.

Rural palliative care provision has been identified as being often of high quality\(^3\), however models of service provision vary considerably between areas. An opportunity exists to combine all that is already good about rural palliative care, with the lessons that can be learned from the specialised models of care that exist in metropolitan areas, to develop a service model that delivers the best achievable quality of care to rural patients.

SPECIALISATION AND STANDARDS

The specialty of palliative medicine in Australia became official in May 2000 with the formal recognition of the Australasian Chapter of Palliative Medicine\(^4\), a chapter established under the auspices of the Royal Australasian College of Physicians. The Chapter seeks to promote clinical, academic, educational and ethical standards in palliative medicine, and has established a broadly accessible 3-year training pathway for specialty training in palliative medicine.
Palliative Care Australia, the national peak body for palliative care in Australia, advocate for all Australians who need palliative care, issued its revised standards document in October 1999 to describe “dimensions and elements of quality in specialist palliative care services.” The document defines Palliative Care as the “specialised health care of dying people aiming to maximise quality of life and assist families and carers during and after death.”

Specialisation of services may not be viewed favourably by all health providers, perhaps understandably so in Rural Areas where specialist support is limited or not available. The PCA Standards document acknowledges that a single set of standards cannot be equitably applied to services with different resources and plans criteria suitable for generalist, or primary level services that utilise a palliative approach, to be developed in the future. There appears to be an ideal opportunity for rural practitioners to be pro-active in developing suitable criteria for standards and requirements in their own sector.

MODELS OF CARE

The World Health Organisation defines palliative care as:

The active total care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms, and of psychological, social and spiritual problems, is paramount. The goal of care is achievement of the best quality of life for patients and their families.

Regardless of the service setting in which such care is provided, the ideals of care expressed in this definition appear to be incontrovertible.

In considering how these ideals of care can be met outside specialist metropolitan services, two service settings have been identified — those providing care for provincial city populations and those serving rural community populations. This dichotomy was observed by Sach and associates, in 1996 when they undertook a comprehensive review of existing rural palliative care services in four Australian states. Sach suggested that service arrangements for a regional provincial city (population of the order of 100,000) could be based on similar principles to those applied to metropolitan communities.

For rural communities, it may be helpful to consider the following potential approaches for service delivery and co-ordination:

♦ “traditional” health care model;
♦ “clinical nurse consultant” model;
♦ formal multi-disciplinary team; and
♦ visiting consultative service.

The “traditional” health care model

This is the provision of care using the ordinary, routine model of care provided to all patients. Typically this involves diagnosis and management of presenting problems by a single practitioner, with referral to other medical specialists if available and deemed necessary, and involvement of allied health and nursing staff if a specific need arises.
For some patients with terminal illness this may provide an acceptable level of care, though the origins of the palliative care movement should be remembered (it was largely the failings of this model of care that gave rise to the alternate hospice and palliative care movement). Further, limitations of this model include the lack of collective responsibility for the care of the patient, family, and other carers, and particularly the lack of peer support for the professional carers involved.

“Clinical nurse consultant” model
This model provides care co-ordinated by a clinical nurse consultant (CNC), a nurse with specialised palliative care skills and experience. The role of the CNC is to liaise with all care providers (general practitioner, specialist medical providers, community and in-patient nursing staff, allied health providers, and patient and family) to help plan and co-ordinate management. The CNC as co-ordinator may assist in the monitoring and evaluation of service provision, act as a knowledge resource for other areas of the health system, and be active in education and training of staff. This may achieve co-ordinated multi-disciplinary care, but by itself falls short of an interdisciplinary team approach. The burden of care may fall heavily upon a single CNC, and peer support for the CNC may be lacking in the absence of a formal team.

Formal multi-disciplinary team
This is characterised by a formal team of designated members who meet together to co-ordinate care. A CNC may be the ideal team leader. Essential members comprise representatives of medical, domiciliary and inpatient nursing staff, plus other available allied health professionals (eg social worker, physiotherapist, occupational therapist) and other staff (eg chaplain, bereavement counsellor, volunteer co-ordinator). Meetings may be regular (ideal) or called when required to discuss management of specific cases. An interdisciplinary, as opposed to a multi-disciplinary team, is one where members of the care team (and patient and family) work collectively beyond the restraints of their traditional roles, towards the shared goal of optimising quality of life for the patient and their family. This is the gold standard aspired to by all specialist palliative care teams.

Visiting consultative service
This may be provided by a visiting (fly-in, fly-out) specialist or specialists, and may be provided in association with a local team approach. The non-elective nature of palliative care, and the need to provide care that is constantly at call, may limit the usefulness of this model. One clear exception, where a visiting service can be particularly useful, is in isolated and remote areas, which require optimal and flexible utilisation of locally available resources with expert support as available. Such support may perhaps ideally be provided at a regional level, particularly from a regional centre that in addition to providing in-patient facilities can offer telephone advice, education, administrative assistance, and periodic visits by the regional team to the isolated communities.
TEAMWORK

Teamwork has been an essential component of palliative care since ever since the birth of the hospice–palliative care movement.

The care of the dying should not be an individual work but one that is shared. Shared with the relative, with all the various members of the staff, spiritual, medical and lay; and, as far as we can, with the patient himself. Where this is so we are left with the sense of completion and fulfilment which makes this such a rewarding branch of medical and nursing care. (Dame Cicely Saunders 1976)

The interdisciplinary team is now central to all metropolitan and larger regional palliative care services, however formal teams are rarely encountered where the base population is below some 50 000.\textsuperscript{7,10} It is inconceivable that a specialist palliative care physician could function effectively without the resource of an organised team, thus those services large enough to support a medical specialist invariably incorporate a formal team. I believe that this constitutes the rate-limiting step for development of team-based care, and one that can and should be overcome by team-participation by primary medical providers.

The 1998 National Palliative Care census\textsuperscript{10} identified a total of eight Palliative Care Teams in existence in Rural Australia, compared with 51 in metropolitan and 31 in regional Australia. As service size is scaled down, it appears that the gold standard of a team approach is often abandoned. There appear to be both logistical and cultural blocks to a team approach.

Logistic problems that may be cited by rural practitioners relate to limited time and funding resources, and indeed the work pressures on busy rural GPs and other rural health providers are well acknowledged. Cultural difficulties relate to traditional and established work patterns of rural GPs occurring in relative isolation from other care practitioners. Rural GPs enjoy participation in holistic care of their patients from cradle to the grave, generally with minimal specialist intervention. Adopting new models of care that involve sharing this participation with other health care staff may be viewed with some dissonance.

However, the burden of care does not diminish with isolation nor community closeness, the requirement of a forum for discussion of patient and family problems, and the need for all involved health care professionals to be involved in service planning and evaluation, all exist in the small rural setting. Indeed the limited experience and limited formal training in palliative care characteristic of non-specialised practitioners, particularly in the light of ever increasing standards and increasing emphasis on specialisation, could be seen as all the more reason to adopt a team approach to care.

THE ALBANY EXPERIENCE

Albany is a small regional centre in the south-west of WA, some 460 kms south of the nearest metropolitan area, with a population of 29 600. Up until 1995, palliative care was delivered using the traditional model outlined above, with no formal co-ordination between the three main service providers: the regional hospital, a community hospice and a domiciliary nursing service.
To assist co-ordination and integration of these services, and improve delivery of care to patients, a multi-disciplinary palliative care team was established in Albany in 1995. The team initially comprised representatives of inpatient and domiciliary nursing providers, a social worker, and a general practitioner with a special interest in palliative care. The GP provided medical advice to the team, and liaison between other GPs and the team, but each patient’s own GP remained the central provider of their medical care. The team met fortnightly, and where patients were identified as presenting management problems, the patients own GP was invited to attend the team meeting. In the first year, there were 23 meetings, 60 patients were receiving care, and no GPs attended.

The following year the client load was unchanged, fortnightly meetings continued, and there were 16 GP attendances. This significant improvement was the result of a Divisions of General Practice project which combined an educational initiative with the then novel approach of funding GPs to attend the meetings. The total cost of funding GP attendance was $763. Clearly a profitable investment, and one that was successful not directly because of the small financial benefit to individual GPs, but because of the signal (through a fee for the service) that attendance at the meeting was an “officially” recognised endeavour.

The neighbouring town of Denmark, population 4000, where local medical services comprise three GPs, a small hospital and a domiciliary nursing service, also established a team that met regularly and was remunerated through the same mechanism. However with clearly smaller numbers of palliative care clients, their team used the meeting as a forum to discuss other non-acute patients (eg rehabilitation, aged care, and psychiatric clients) in their community.

These local examples have continued successfully since, and demonstrate that a team approach that incorporates the general practitioner as the central provider of medical care, can be viable even in small rural populations of 4000 or so. Although initially reliant upon special project funding, the Commonwealth’s enhanced primary care initiatives provide an alternative funding source.

**ENHANCED PRIMARY CARE INITIATIVES**

The Enhanced Primary Care (EPC) package, component of the Commonwealth’s Primary Care Initiatives of the May 1999 Federal budget, provides an ideal opportunity to encourage GPs to take part in team-based care. The Medicare Benefits Schedule provide item numbers for care-planning and case-conferencing, services to which our patients are entitled. Of 73 547 services in the period Nov 1999 to July 2000, 11% were care planning items, whilst case-conferencing accounted for only 3% (metropolitan and rural for all chronic medical conditions)\(^1\).

Some limitations to access of EPC items exist, particularly with regard to discharge planning from inpatient care, and the current exclusion of patients who are resident in Nursing Homes. Furthermore, the MBS items relate only to general practitioner remuneration, and no specific mechanism yet exists for remunerating other participating health care providers. Nevertheless, the initiatives have the potential to encourage the cultural change in GPs necessary to embrace multi-disciplinary care.
Such improvement in integration of general practice with other primary care and community providers has been desired by the profession itself for some time — such integration was a part of the vision for the 1992 GP Strategy. The emphasis is reframed in the 2000 comprehensive Report on General Practice in Australia, that states integration of care “will be particularly relevant as Australia attempts to develop a primary health care agenda that seeks to place general practice in the centre of a multi-disciplinary team approach to the care of individuals and populations.”

One reason why uptake of team-based care items may have been limited, is the difficulty in establishing team infrastructure and unfamiliarity with the process. The process of establishing a team is straightforward, though considerable work and expertise is required to develop and maintain the team, for which there are many excellent reference texts for guidance. Now that EPC items are here to stay, an opportunity exists for those rural services that do not utilise a team approach to look at ways of incorporating it into their service.

GUIDELINES FOR RURAL SERVICE DEVELOPMENT

In 1998 the Commonwealth Government issued a 5-year national strategy that endorsed the 1994 Australian Association of Hospice and Palliative Care standards. Whilst awaiting revised criteria for rural services, these original standards serve well to reflect the underlying philosophical principles, and articulate clearly what palliative care is about. Specifically:

1. Effective management of pain and other symptoms and the provision of psychological, social and spiritual support occurs, when requested and where required, in a culturally appropriate manner.
2. The patient, family and carers are recognised as the unit of care.
3. The care of the patient is based on the needs and wishes of the patient.
4. Multi-disciplinary teams provide integrated medical, nursing, allied health and community services to patients and families.
5. Bereavement support for the patient, family and carers is integral to palliative care.
6. Effective palliative care service delivery occurs in the context of an informed health sector and palliative care information and education is available to the wider professional and local community.
7. Effective palliative care services are committed to quality improvement and research in clinical and management practices in palliative care.
8. Effective administrative arrangements at Commonwealth, State/Territory, community health and support services levels provide palliative care services that are appropriate for the palliative care needs of local communities.

An essential requirement in establishing a palliative care service is prospective identification of those clients eligible to receive palliative care. Whilst this step may appear obvious to metropolitan services that await referral to their services before commencing care, the boundary may not exist for smaller rural services in which the same providers provide care both before and after “referral” of palliative patients. Separate funding sources for palliative care makes this step essential if such funding is to be accessed, and subsequent service provision needs to be separately identified.
Integration of services and co-ordination of care across multiple disciplines is dependent upon effective information and communication systems. In rural Western Australia, the WA Rural Palliative Care Database is an electronic health record that assists these endeavours by maintaining, in electronic medium, a list of patients against which service provision, patient symptomatology and functional status can be recorded and shared by all service providers. Comprehensive reporting tools serve to assist monitoring of service provision, and facilitate clinical audit and ongoing service evaluation.

**EVALUATION**

The objective in adopting new models of care is to improve the quality of service available to patients. The National Strategy for Palliative Care defines high quality services as those which “are locally and readily accessible in an appropriate setting, multi-disciplinary, of a high clinical standard, clinically appropriate, sensitive and responsive to the social, psychological, cultural, spiritual and other specific characteristics of individuals and their families and carers.” Comprehensive Performance indicators have been developed to assist accreditation of services and monitor adherence to existing standards.

Assessment of quality in palliative care at a patient level is not straightforward, where the common endpoint of death is universal and the disease process unrelenting, affecting all dimension of a patient’s life. Since the over-riding aim of all palliative care provision is to maximise quality of life for patients and their families, the best outcome measure would be a comprehensive assessment of quality of life. The literature relating to quality of life in palliative care is vast, though conceptual models to assist this process in practice are yet to be satisfactorily developed and implemented. Nevertheless, much progress has been made in evaluating palliative care, and it is no longer acceptable to provide care for dying patients without attempting to measure and improve the effects of this endeavour.

**SUMMARY**

This paper addresses possible models of rural palliative care delivery with a clear emphasis on the need for teamwork. The considerable pressures from the government, the national body of Palliative Care Australia, our specialist colleagues and general practice have been outlined. The environment of primary health care is in a state of change and we have an opportunity to shape this change to the benefit of our patients. Whilst specialisation of palliative care may be viewed by some rural practitioners as a threat to the traditional model of care that has served so well over the years, it could better be viewed as a resource of ideas which can be considered and adopted, where practicable, for the benefit of our patients. A recent British Medical Journal editorial observed that the pioneers of palliative care have been arguing for 30 years that special care should be offered to the dying. There is, however, something paradoxical about creating a specialty to cater for something that happens to us all. The trend now is for the lessons learnt by palliative care physicians to be reclaimed by everybody.
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