

The Griffith Area Palliative Care Service: A Pilot Project

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Abstract

In September 2000 the Commonwealth released, as part of its National Palliative Care Strategy under the Australian Health Care Agreements, a National Framework for Palliative Care Service Development. The new National Framework stressed an important set of values to guide models of palliative care delivery. It notes that the challenge is to secure the place of palliative care as an integral part of health care across Australia, routinely available within local communities to those people who need it. Care and support for people who are dying and their families need to be built not only into health care services, but also into the fabric of communities and their support networks. While few would disagree with this, little is known about how best to achieve it in rural Australia. The Griffith Area Palliative Care Service (GAPS) is a two-year pilot project delivering a palliative care service through a truly integrated approach to care for patients, their carers and families within the Griffith Local Government Area and Carrathool Shire areas. This paper describes how GAPS is successfully meeting the challenges of service provision to rural and remote areas.

Background

Griffith (census population 23,805) is the regional centre for the Murrumbidgee Irrigation Area of southwest New South Wales. Its service catchment has a population of approximately 33,500 residents (Australian Bureau of Statistics 2002). Historically, the majority of ambulatory palliative care in Griffith has been provided by General Practitioners (GPs). Service provision has included both practice-based and domiciliary care. A visiting oncology clinic has continued to provide a fortnightly outreach service from St Vincents Hospital Sydney since 1996. There has not however been a history of Palliative Care specialist services on-site in Griffith.

For at least the past decade, domiciliary nursing has been provided on referral by registered nurses from the Griffith Base Hospital Oncology/Palliative Care Unit, the Community Health District Nursing Service and a private community nursing agency. Unfortunately there had been little coordination in care between the local nursing services, with subsequent inconsistencies and barriers to continuity of care.

In 1998 an external review of palliative care services across the Greater Murray Area Health Service benchmarked performance against contemporary national standards (Sach 1998). Numerous service gaps were identified, and recommendations made. In particular, deficiencies in the delivery of palliative care services in the Griffith area included:

- An apparent inequity in access to ambulatory and domiciliary services and community support between oncological and non-oncological patients in palliation;
- After 5pm and at weekends (out-of-hours) medical services in the primary care setting were uncoordinated. Some GPs attempted to cover services for their registered patients 24hours/7 days week especially in cases of terminal illness, while other GPs provided no after-hours service. From the GP's perspective, the job was exhausting and demanding;
- No formal out-of-hours system for domiciliary nursing support existed. As a result out-of-hours Emergency Department attendances by palliative care patients were high. In the absence of clearly defined clinical guidelines or standardised reference materials, this invariably entailed long waits, lengthy examinations by the resident medical staff and often admission to the ward under the care of the nominated specialist on-call, with or without notification to the normal GP;
- There were no dedicated palliative care beds at Griffith Base Hospital;
- Patient medical records for admissions to acute care failed to reflect the chronicity and complexity of medical problems. It was apparent that many diagnostic tests were duplicated or redundant;
- There were no operational links between the Griffith Base Hospital Oncology/Palliative Care Unit, District Nursing and private community nursing agencies;
- Data collection on the incidence, scope and tracking of palliative care cases was incomplete and inconsistent between local service providers. This clearly failed to meet national standard requirements for a minimum data set; and
- There was no formal volunteers' network to support patients and carers, except that provided by the local branch of the Cancer Patients Assistance Society.

The Griffith Area Palliative Care Service (GAPS) project seeks to demonstrate that enhanced access to an integrated palliative care service for terminally ill people, their carers and families is achievable and sustainable within a rural context. In so doing, the project is piloting a model of care that translates the National Palliative Care Strategy into integrated services that work for rural Australia. The project began on 1 October 2001.

Methodology and implementation

In accordance with recommendations of the Sach report (1998), a working party of key local stakeholders was formed in September 1999. Terms of reference for the working party were to analyse the key systems issues, discuss the feasibility of the Sach Report recommendations, and determine options for sustainable service enhancements consistent with the National Standards. Key stakeholders on the working party included Griffith Base Hospital management, Community Health management, Murrumbidgee Division of General Practice, the Griffith Nursing Service, ministers of religion, plus representatives from GPs, nursing and the community.

The working party developed a service model centred on integrated delivery of care utilising the existing providers as the resource base. Successful parallel submissions for a 3-year pilot project were funded by the Australian Department of Health and Aged Care to the Murrumbidgee Division of General Practice and by the NSW Health 'Priority Health Program' to the Greater Murray Area Health Service respectively. The University of Wollongong's Centre for Health Service Development successfully tendered to provide an external evaluation of the project. Key elements of the model are included in Figure 1.

Figure 1: Key elements of the Griffith Area Palliative Care Service pilot model

GOVERNANCE AND STAFFING

Administration of the project by a board of governance including senior management from the Greater Murray Area Health Service and Murrumbidgee Division of General Practice plus representatives from pastoral care and the community; and appointment of a Project Coordinator jointly funded by the Greater Murray Area Health Service and Murrumbidgee Division of General Practice for the initial 3-year term of funding.

24-HOUR ACCESS

Provision of a 24 hour 1800 number for advice, intake, referral and coordination of out-of-hours call-outs as required;

Formal nursing on-call roster after hours including registered nurses from all agencies (organised and managed by Greater Murray Area Health Service);

Formal GP on-call roster out-of-hours funded solely through Medicare Benefit Schedule claims (organised and managed by Murrumbidgee Division of General Practice). This includes an agreement that attendance for ED presentations will be encompassed within an MBS claim, and not levied against Griffith Base Hospital as a GP-Visiting Medical Officer (VMO) call-back; and

Formal agreement with Griffith Base Hospital visiting Medical Officers on-call for the transfer of GAPS-registered patients to a palliative care team medical officer next day following an emergency admission.

CASE MANAGEMENT AND REVIEW

Joint agreement from all agencies on a single set of policies, procedures and clinical guidelines for the management of patients registered with the GAPS service;

Joint intake options by the case management team;

An integrated patient-centred medical record that traverses all services involved in the patient's care;

Weekly case management review involving oncology/palliative care nurses, community nurses, private nursing agency nurses, GP representatives, and allied health, in liaison with Griffith Base Hospital Emergency Dept and Pastoral Care;

Accredited volunteer screening and training program, provided by the Mercy Hospital, Albury; and

Education programs for Medical Officers, Registered Nurses, pastoral care and volunteers.

ENHANCED PRIMARY CARE

Following the weekly case reviews, coordinated, systematic uptake of Enhanced Primary Care (EPC) items.

INFORMATION MANAGEMENT

Trial of the palliative care information system (PalCIS) for patient registration and clinical information;

Establishment of a Minimum Data Set that satisfies National Standards for Palliative Care;

Trial of palm pilots to collect the minimum data set at the point-of-care; and

Routine collection of baseline data, monthly monitoring and progressive evaluation against nominated Key Performance Indicators.

Governance

The governance committee is composed of each of the major stakeholders and has an independent chair. This committee is closely involved in the detail of the project and makes decisions on policy and resource use. The governance committee is well placed to ensure that the project remains on track. It gives careful attention to the areas of financial and clinical responsibility and to the quality of project reports and monitoring. This ensures that feedback to the community is maintained and that the project can be seen to act properly in addressing its task (Centre for Health Service Development, 2001). In conjunction a clinical working party has been responsible for developing the various clinical guidelines, strategies and protocols upon which the project is based.

24-hour access

A 24-hour free phone number has been provided for patients and families, and is also used by Emergency Department staff. Calls are screened and triaged by the registered nurse. The service offers support, advice and management including domiciliary visits if required. Seventy percent of Griffith GPs are involved, and those without VMO rights to Griffith Base Hospital have been granted privileges for palliative care. Patients can be directly admitted to the ward, bypassing the emergency department, if required.

Case management and review

A multidisciplinary palliative care team aims to bring together individuals with a diversity of training who share the goal of improving the quality of life of the patient (Ajemain 1995). Each team member will have particular expertise and training and will be responsible for making individual decisions within his or her area of responsibility. To truly work as a team, members must be willing to subordinate their personal agendas for the good of the whole and open to accept the contributions of other team members, particularly in discussing plans for future action. In the multidisciplinary team the identity of the team is meant to supersede individual professional identities. In this context members should share information and work together to develop goals; ideally, leadership is shared among team members depending upon the task at hand, because the team is the vehicle of action the interactional process is vital to success (Lowe and Herranen 1981; Maddocks 1997).

The composition of any multidisciplinary team will vary depending upon the degree of the development of the program, the objectives of the program and the available resources. For example the GAPS project service team includes medical officers, nurses, allied health, pastoral care, and volunteers. Directed meetings are essential for mutual support, adequate hand over and continuing communication. The situation of a patient with a terminal illness may change quickly, hence the regime providing comfort today may be inadequate tomorrow. The GAPS project uses weekly case review meetings as an essential vehicle for planning and evaluation, and an avenue for addressing potential problems and executing appropriate measures as required. A weekly one-hour case review meeting has been a cornerstone of the GAPS project since its commencement on 2nd October 2001.

The GAPS project case review meetings are evolving, and have proved critical in developing closer links between the agencies involved due to the sharing of clinician's experience and knowledge in their joint delivery of care. Care options are looked at in a multidisciplinary climate ensuring minimal conflict arises from ensuing decision making. The GAPS project has strived diligently to implement systems conducive to a work environment where the objectives of the team aim to supersede professional identities.

Enhanced primary care

A pivotal point in the Griffith-based review of local palliative care services came with the Commonwealth's launch from November 1st, 1999 of the 'Enhanced Primary Care' (EPC) Medicare Benefits Schedule (MBS) items. Comprising 21 items in all, the goal of the EPC package is to improve the health and quality of life for older Australians and people with chronic conditions and multidisciplinary care needs through enhancing the delivery of primary health care services. Designed to support the role of the general practitioner in the provisions of coordinated multidisciplinary primary health care, stakeholders in said review came to realise the potential in EPC items for leveraging change in the delivery of local services to a target group that clearly matched the criteria.

Consistent with both State and Commonwealth priorities, uptake of EPC item groupings relating to 'Care Planning' and 'Case Conferences' subsequently became a key performance indicator for the planning of the GAPS project. On the other hand, uptake of the EPC item grouping related 'Health Assessments' were considered less relevant in the palliative care context, given their focus on minimising potential health risks and provide improvement in health care outcomes such as quality of life and efficiency of care.

The GAPS model of care identified the weekly multidisciplinary case management review as the key tool for engineering uptake of the EPC items (Murrumbidgee Division Of General Practice Palliative Care Submission, 2000). In turn this strategy is consistent with the National Palliative Care Strategy. Specifically, Objective 3.1 states in part that, care for the person who is dying, and their family should be coordinated through partnerships between the person, the family and the service providers (Commonwealth Department of Health and Ageing, 2000). Further, this is also mirrored in the standards of palliative care provision by Palliative Care Australia (October 1999). Specifically, Standard 6.1 states that an interdisciplinary team should exist to provide coordinated medical, nursing and allied services to the patient and family. Further, it states that the teams should meet regularly to plan, review and evaluate the care of the patient and family and to regularly discuss issues relating to the provision of services.

To date the GAPS project has reviewed an average of 20 patients per week through the multidisciplinary meetings. Data from the meetings is recorded including statistics on general practitioner and team attendance. It therefore seems appropriate to implement a strategy whereby EPC items can be achieved with a minimal workload for professionals from other disciplines.

Education was sourced through the Murrumbidgee Division of General Practice, and for ease of use, staged implementation will occur. Due to the longitudinal nature of care plans and the complexities involved they will be implemented at a later date.

Implementation of Case Conferencing EPC items first occurred on the 10 January 2002. Case Conference involves the formatting of the proceedings of the interdisciplinary meeting and therefore has less impact in terms of workload for all the people concerned. The administrative assistant takes a summary of the discussion/plan for the patient. The palliative care coordinator reviews this and the information is then entered into the PalCIS database (which fits in with EPC guidelines as laid down by the Royal Australian College of General Practice). Once formatted copies are sent to relevant service providers, the on-call folder, the patient-centred notes and at present the general practitioner copy is being sent to the accounts department of the local practice. Once the EPC number has been claimed it is transferred to the patient's GP notes. Checklists have been designed to ensure no gaps are left and administration is done in a timely and effective way. The amount of time required in administration for this process is to be assessed and evaluated on an ongoing basis. On successful evaluation of Case Conferencing, Care Plans will then be added.

The project demonstrates a strong commitment of general practitioners to multidisciplinary collaboration, with a total of 803 GP team attendances to date. In turn, this has effected a total of fifty-five completed EPC 'case conference' claims, averaging 2.62 case conferences per week. It is clear that quality of care and the increase in knowledge and communication are the driving forces for GP attendance at case conferences as opposed to financial reward, given this meeting is unpaid for the local doctors except for some financial redress through the subsequent uptake of EPC items.

Information management

The GAPS project chose to trial as its information system 'PalCIS', a clinical information system designed by Unique Database Solutions for use exclusively with palliative care. It's forerunner, the 'West Australia Rural Palliative Care Database' (WARP CD) is in current use at eight sites in West Australia. The WARP CD was the result of ongoing development of the Albany Palliative Care Team Database, used since 1995 to assist the development of a coordinated team approach to palliative care in that Western Australian community. The database records the following:

- Demographic details;
- Diagnoses, metastases and complications;
- Inpatient, Ambulatory and Domiciliary Service provision;

- Symptomatology (WA Symptom Assessment Scale);
- Functional Status;
- Professional and Family Carer Details; and
- Consultations and Care Plans.

PalCIS features an advanced, user-friendly interface via mouse and/or keyboard. An emphasis on visually enhanced feedback of the entered data is maintained throughout the application to facilitate its use for decision support purposes. PalCIS is ideally suited to use by multidisciplinary services operating from multiple sites. The data exportation, importation and merging tools allow data for single or multiple patients to be shared between sites and services using securely encrypted files. PalCIS incorporates a flexible tool for creating links to existing patient information systems to enable the importation of patient demographic details.

As Schneider (2001) highlights, practitioners are always searching for any tool that saves time and decreases the amount of information to remember. Technology and its use in the healthcare field is steadily growing (Wilkinson 2001). The PalCIS database is portable via the use of an integrated palm pilot; users can export their current list of patients for on-the-road reference and for the recording of new domiciliary visit details for later re-importation into PalCIS. Recording of information at point of care provides obvious benefit to the practitioner and service and consistent with findings reported by Griever (2001), there is no evidence to date from the project where patients have found providers' use of the palm pilot at the point of care to be intrusive. Indeed, anecdotal comments suggest patients appreciate the extra information now brought to their healthcare. The initial trial of palm pilots has resulted in the further purchase of units for use in data collection and information resource by care providers.

People admitted to GAPS have one integrated patient-centred medical record. The aim is to ensure greater continuity of care and more efficient services. Patients will no longer have to repeat their medical history on each presentation to each new service and more importantly to a service that has a high throughput of staff such as Griffith Base Hospital Emergency Department. The patient keeps their own record with them at home and all professionals involved in their care record information directly into the medical record.

Collection of data for key performance indicators

Higginson (1996) states that when death is imminent, there is no second chance to improve the quality of care for the patient and family. Perhaps more than in any other aspect of care, quality of care for people who are dying must be priority. The past few years have seen palliative care move from a marginalised part of health care dependant on special funding to a core component of Australian health care delivery. Like other components of health care, palliative care is subject to scrutiny in the areas of quality, effectiveness and efficiency both from within services and from health care funders and administrators.

As the project progresses, issues of quality are increasingly dominant. Evaluation of the project poses many data issues, with each funding entity requiring differing reporting structures. In report writing alone, documents need to be prepared for the following:

- GAPS Board of Governance;
- Murrumbidgee Division of General Practice executive;
- The Commonwealth Department of Health and Ageing; and
- Greater Murray Area Health Service – Chronic & Complex Care Program (NSW Health).

In addition the project is also required to collect information for Palliative Care Australia. In order to try and simplify reporting, an evaluation summary has been produced. Greater Murray Area Health Service in particular requires substantial quantitative data in order to meet its requirements with NSW Health through the 'Chronic & Complex Care Program' initiatives.

Outcomes and evaluation

The GAPS model of care involves three process elements. The first is a more coordinated and integrated application of existing resources. This requires formal commitment from multiple key agencies, providers and community representatives to the objectives of the project.

The second is an investment in new resources. A major component of this investment was in the development of tools that will not require additional recurrent funding (e.g. integrated patient-centred records, clinical guidelines, GP on-call roster, case review meetings, information system implementation and external evaluation). Additional recurrent funding is required where gaps in service delivery fell significantly short of national standards (eg, RN on-call roster, 1800 phone line, assorted variable goods and services linked to increased activity).

Finally, there is formal evaluation. The Centre for Health Service Development (University of Wollongong) has been commissioned to externally evaluate the GAPS project. The evaluation question at this point is whether the project structures and activities, the design and planning of the interventions and the information tools and systems to be used are in line with the aims of the initial proposal.

The objectives of the project are ambitious – to establish a model of care which is both sustainable in the long term and generalisable to other rural settings. Whether these objectives can in fact be met, and whether the evidence will be clear and well supported by data, are the present focus of the evaluation.

Future scope

Service plan objectives to further develop the GAPS pilot project currently include the following:

- To roll out to further sites to test which components of the model are transferable;
- To strengthen links with a tertiary specialist palliative care centre, with a view to developing a consultative model rather than visiting clinics. Preliminary negotiations on developing a partnership with Braeside Hospital & South West Area Health Service have commenced. The feasibility of using existing telehealth infrastructure is to be investigated;
- To develop link services with local nursing homes. This will include the provision of nursing consultancy and education programs;
- To enhance the psychosocial input to the multidisciplinary team with the development of local social work/welfare services; and
- To review the role and capacity of the existing Oncology/Palliative Care Clinical Nurse Consultant (CNC) position based at Griffith Base Hospital. Specifically, the feasibility of further developing and enhancing this role to increase the focus on primary care outreach and driving inter-agency consultancy is to be investigated.

Conclusion

For the first time in Griffith, multiple state- and Commonwealth-funded providers, private agencies, pastoral care and consumer advocates have come together to resolve problems collaboratively. While it is not possible to conclude from this work in progress that all issues have already been resolved, it is clear that the project has developed and implemented several sustainable structures and processes with demonstrable links to both mainstream health care services, and to consumer and community interests. This includes an innovative system for joint inter-agency and community governance, which does not impede the routine operational management of participant agencies, yet ensures the objectives of the conjoint service are properly administered. Further, the project is placed within a broad peer review and education framework designed to enhance quality and develop common understandings between key participants applying a system of integrated rural palliative care.

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