

Submission to the Queensland Parliament Health and Community Services Committee Inquiry into palliative care services and home and community services in Queensland.

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Personal information

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Provision of palliative care services from a community and general practice perspective.

Summary

Much of palliative care is delivered in the community, and general practitioners are responsible for much of the medical care. There are significant current and potential problems that limit the ability of GPs to provide this care. In spite of this, most GPs willingly undertake known palliative care patients. However, there are a large number of people who are in the final stages of life, but these are not tacitly recognized by the health professionals who care for them. Most do not have cancer, but suffer a range of chronic non-malignant conditions or frailty. Virtually all GPs encounter them, knowingly or not, because virtually all GPs manage patients like this.

Facilitating GP care of these patients utilizing a palliative approach will facilitate improved care and almost certainly reduce unplanned hospital admissions. The same applies to hospital staff and emergency department staff.

A whole of system approach which brings together hospital, specialist care and community-based care is a preferred approach. A successful model of palliative care delivery has been developed in Catalonia, Spain. The lessons of the Catalan program can be applied in Queensland, with modifications to account for the State-Federal

allocation of health funding responsibility. A case management approach, with processes developed to provide appropriate input from different levels of care could be highly effective, but does not currently exist. This approach would have the added benefit of continuous, case based education of GPs, leading to an improvement of the system-wide knowledge and skills of basic palliative medicine. It would also lead to improved intersectoral collaboration for individual patients. Current work to develop an Australian version of case-based care planning is currently underway by the University of Queensland and West Moreton Community Health Services. The principles and practices of a Catalan-style approach should be developed and tested as an extension of the BASIC-PC program in the West Moreton Health District, with the intent that it be rolled out state-wide.

Background

The definition of General practice is the comprehensive care of the whole person in the context of their family and community. (1) Palliative care is the an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. (2) There are clear parallels between the two. A palliative *approach* as per the WHO definition is an approach to care delivered by non-specialists as well as specialists, that adheres to this definition. All health professionals should be familiar with this concept. Palliative *care* refers to care delivered by generalist and specialists alike. Palliative medicine is the specialist branch of medicine that has expertise in palliative care. (3)

Epidemiology of palliative care

In high income countries with ageing populations, around 75% of citizens die due to advanced chronic, conditions (4), mainly organ failure (cardiac, lung, liver, renal,) , and neurological progressive conditions, and some other less frequent as pediatric advanced diseases. Cancer is responsible for 25% of all deaths. Recent research has identified the prevalence of patients in need of palliative care approach. (5, 6)} Two per cent of the population suffers advanced complex chronic conditions (6) and around 1.2-1.4% have a limited life prognosis of one year. These patients are mostly living at home or in nursing homes, and looked after by primary care services. They are likely to be cared for by carers who are either spouses (and therefore probably as old and with their own medical and functional issues), or adult children with work responsibilities, or who are parents of children themselves. (7)

Specialist palliative care services are almost exclusively centred on the care of patients with cancer – advanced cancer comprises 85-90% of the clientele of most palliative care services. (8)

The impact of these conditions comprises a high degree of suffering, high needs and demands of care, frequent decisions about end of life treatment, and high use and consumption of resources, mainly emergencies, acute hospital admissions, drug use,

and cost. We do know that 70% of the costs of health care are spent in the last 6 months of life (9, 10)

The conventional care of these patients is reactive, fragmented, and based in emergencies and crisis.

The role of general practice in palliative care

As stated in Professor Patsy Yates' submission to this committee (11), it is important not to forget that much palliative care takes place in the community. Approximately 90% of the last year of life is spent at home, with the care being delivered by community based agencies. Much of the medical care of these people falls to the GP. Two studies in Australia show that 75% of GPs see palliative care as a central part of their care.(12, 13). While it is optional in urban settings, it is an inevitable part of GP care in regional and rural settings (14).

The remainder of people who die of a disease with a predictable palliative phase have a combination of frailty and multi-morbidity, end stage organ failure like heart failure and chronic obstructive pulmonary disease, and dementia. Many of these patients are the very old, they are likely to be living in the community and not aged care facilities. (8)

Whether GPs realize they are providing end of life care or not, they are.(15) One of the key issues is to encourage GPs to take an end of life perspective in the care of these people, in addition to a purely medical perspective. The current perspective aims to manage the many medical problems they have. The extra perspectives that comprise an end of life perspective include:

- Considering best practice management of the symptoms that the person's underlying conditions are likely to produce (eg nausea, breathlessness, pain), and planning for them. This includes treatment strategies to prevent them from occurring, and strategies to treat emergency escalations.
- Including in the plan for the provision of out of hours medical care, including telephone consultations.
- Consider the psychological and spiritual burdens that will escalate at the end of life
- Ensure advance health directives and enduring power of attorney are in place
- Be cognizant of the needs of the carer, and systematically identify and address the issues. Caring for the carer reduces their burdens and assists the patient by ensuring that the carer is in the best state possible to care for them. Carers' inability to continue care is a major reason for admission to hospital. (7)

Much of this care is routine in general practice, and there is little extra that needs to be done. In Canada, the presence of a regular GP reduces unnecessary emergency department visits and hospital admissions. (16)

However, there is a looming problem. The profile of GPs not willing to undertake this role, or pass it on to palliative care services, is very close to the demographic of

significant sections of the general practice population of the future: that is- younger GPs, non-Australian trained, employees rather than practice owners, part time and female.(8) Rhee's comprehensive survey (13) outlines the reasons for non-participation. Issues include unwillingness to do home visits, responsibilities outside of practice (especially parental responsibilities), lack of confidence in their knowledge and skills, and perceived lack of specialist support.

There is a clear mismatch between some GPs perception of palliative care, and the care they actually deliver to people with advanced chronic disease now. Some of this mismatch is a misplaced perception by GPs that palliative care is somehow different to what they already do. Some are unwilling to provide the extra care that is clearly required.

An approach that encourages GPs to participate in palliative care may be nothing more than broadening their perspective for patients that they already recognize as seriously ill, frail or both. In the first instance this requires recognition that these frail people may die and therefore need the broader focus outlined above. Secondly, they need to have the knowledge of what to do to prevent symptoms from emerging, and how to prepare for symptom care when expected crises arise. Thirdly they need to develop care plans that consider the non-medical issues mentioned above.

Hospital and specialist health sector care

Given that most people who die have a period where serious ill health brings with it referral to hospitals and health services, the question arises whether the broader perspective required for caring for the dying is considered in these sectors. There are no data that answer this question, and this is an urgent research need. It is likely that there is implicit recognition that death may be an outcome in the near future. However what is not certain is whether this translates to adopting an overt palliative care approach over and above standard medical care. If this does not happen, it is quite likely that treatment will focus on the medical symptoms only, potentially more aggressive treatments may be instituted to prevent further deterioration. This translates to more health sector costs for little gain, AND missing important facets of necessary care.

The Catalan Palliative Care program

Professor Xavier Gomez-Batiste is a palliative care specialist from Barcelona, Spain, and who is currently in Queensland on an academic exchange. He has developed and implemented a state-wide system of palliative care delivery which is comprehensive, and based on district-by-district palliative care plans being developed. (17) The system has been adopted across the whole of Spain. Much of the palliative care is delivered by community based teams. The model for this care is set in Figure 1. Note that their system is a wholly state based service, with no commonwealth / state service split. Therefore, while the concept of this model is commendable and has evidence of clinical and economic efficacy (18), the ability to translate it to a Queensland setting without amendment is challenging. There is an estimated 3,000 euro savings per patient per six weeks of public health care with this model in place (18) .

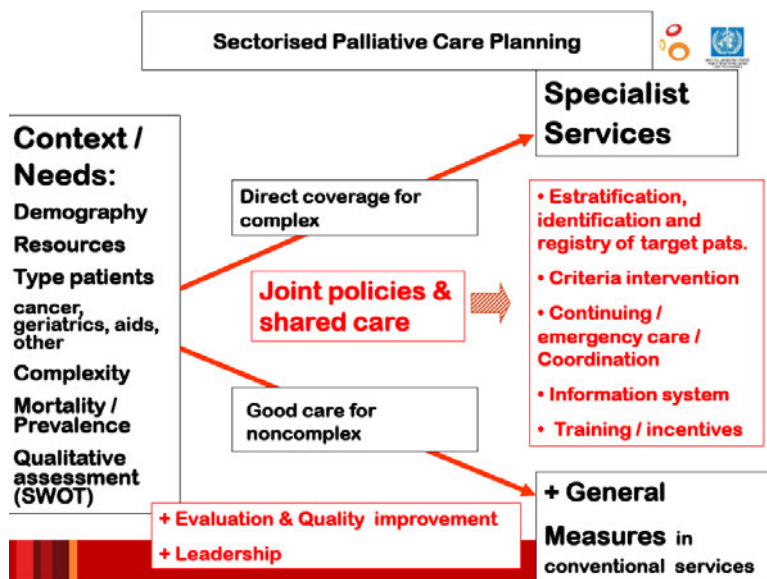


Figure 1- Conceptualisation of the Catalan Palliative Care Plan, developed district by district.

New concepts in planning and implementing palliative care

In the last decade, there have been identified several challenges for innovation of palliative care planning, consisting in the early identification and care of patients in the community, the palliative care approach to be provided in all settings, specially in the community by primary care services, the care of chronic non-cancer patients, and the use of case-management and advance care planning methodologies to look at them efficiently. (19)

The principles are:

- Coverage for all patients in all settings
- equity
- quality
- accessibility
- sustainability

with a public health and community perspective (as most patients are in the community)

The **natural setting for planning** is going to be the district (20), in where rational policies adapted to their unique characteristics include

- needs assessment (quantitative: prevalence studies or qualitative, as looking at the performance of existing services and identifying weak points)
- Identification of patients in need, early, preventive, and in their community services (Nature of relevant patients discussed above)
- Definition of the model of palliative care services

- Case management and advance care planning as main methods of implementation
- Describe of the coordination, criteria for intervention, roles in emergency and continuing care
- Actions in every service to improve the quality of palliative care
- Training and research
- Evaluation of results

The **key factors and processes for development** can include:

- Leadership (clinical and organizational)
- Catalytic investments (small implementations leading to large mid-term effects)
- Prevalence studies (to assess the real needs)
- New role definitions (nurses as case managers, clinical leaders at the district level)
- Empowering community services to identify and care
- Starting pilot projects addressed to some populations at risk or small districts and good evaluation
- Reallocating resources (beds into palliative care, clinical case management nurses, liaison sisters, GPs with special interest, etc)
- Feasibility (mainly related to good leadership)

The **main characteristics** of a rational planned project are:

- Based in the community
- Preventive
- Planned
- Efficient
- Based in a early identification, measures in all services, and integrated care

The **expected main results** of a planned, preventive, rational model are:

- Effective in addressing the needs of patients and improving their QoL
- Reduced suffering of patients and families
- Reduction of emergency use, length of stay, and admissions into hospital
- Cost reduction (reduction of hospital stays, lower cost of palliative care beds, higher probability of death at home)
- High satisfaction of patients and families
- Satisfaction of professionals(20)

A review of the Catalan program indicated that there were deficiencies in care, which could largely be met by timely identification of the relevant patients. The changes in health care approach which arise from early identification are outlined below (Table 1)

Table 1. Conceptual transitions in Palliative Care in the 21st Century



<i>FROM</i>	<i>Change TO</i>
Terminal disease	Advanced progressive chronic disease
Prognosis of weeks or months	"Limited life prognosis"
Cancer	All chronic progressive diseases and conditions
Disease	Condition (multi-pathology, frailty, dependency, .)
Progressive course	Frequent crises of needs and demands
Mortality	Prevalence
Dichotomy curative - palliative	Synchronic, shared, combined care
Specific <i>OR</i> palliative treatment	Specific <i>AND</i> palliative treatment needed
Prognosis as criteria for intervention	Complexity as criteria
Rigid one-directional intervention	Flexible intervention
Passive role of patients	Advance care planning / Autonomy
Reactive to crisis	Preventive of crisis / Case management
Palliative care services	+ Palliative care <i>approach everywhere</i>
Specialist services	Actions in all settings of health care
Institutional approach	Community approach
Fragmented care	Integrated care

Gómez-Batiste X et al, BMJ SPcare, 2012 in press
 Gómez-Batiste X et al, Current Opinion in Supportive Palliative Care, 2012, in press
 Gómez-Batiste X et al, Medicina Clínica, 2012, In press



He has recently concluded research that uses a set of screening questions to find patients who may die within a year. (21) These comprise 1) the "surprise question" ie "Would you be surprised if this person were to die n the next 12 months?"; (6) 2)General clinical indicators of decline, which incorporate physical signs like weight loss, plus recent acceleration of decline; and 3) specific symptoms relating to specific syndromes, or accelerating unplanned hospital admissions or both

His findings are that, in a typical Catalan GP practice, approximately 7% of patients over the age of 65 fulfill the Surprise question + 2) +3). Sixty-one per cent of these patients were at home and 24% were in aged care facilities. In an acute hospital, 25% of all patients were at this level (6). Clearly taking a palliative approach to the care of that number of patients is a challenge.

Challenges to palliative care in the Australian mixed funding system.

Based on the Catalan experience, the development of a system wide approach of palliative care plans developed at the health district level, and delivered by early case identification could provide a potent approach to care, which will reduce overall system costs.

The Australian health system has a split funding model, with the Commonwealth largely taking responsibility for services in the community, and the state assuming

responsibility for services in the hospital system (and Community Health services). The problem is that effective care planning requires a system-wide approach.

What is possible for a state based health system responsible for hospital and sub-acute care, is to identify cases within their system that may benefit from a palliative approach, and have in place a means of planning a joint public health-community based care in conjunction with the patient's GP. This requires a case management approach.

Such an approach is being trialed now. Consideration should be given to a sustained effort to adapt this approach to the broader public hospital system, and formally test its efficacy. That is, consider broadening the approach to involve any Queensland Health patient with multi-morbidity, poor functional capacity, general deterioration (eg weight loss, multiple admissions to hospital, persistent cutaneous ulcers)

The BASIC-PC (Better Assessment, Support and Interdisciplinary Collaboration – Palliative Care) pilot project

This project is part of the work of an NHMRC funded Centre for Research Excellence based at the University of Queensland Discipline of General Practice, which is examining the interface between primary care and secondary care. The premise is that the combination of well-trained GPs working in conjunction with a relevant specialist will improve efficiency, and deliver outcomes at least as good as standard care. There are projects being developed in diabetes care and advanced heart failure, as well as palliative care. Professor Mitchell heads the BASIC-PC program for the CRE.

The BASIC-PC project is being conducted in Ipswich. It begins with the Queensland Health Community Health Heart Failure and Lung Health services identifying patients they believe are within months of the end of their lives. A case conference between the patients' GP and a palliative care specialist and the relevant nurse case manager takes place at the GP's surgery. A palliative care plan is developed by the participants, A discussion with the patient about what changes to care could be implemented is conducted by the nurse and/or the GP. Medicare funds the cost of the GP and the Palliative care doctor, and community health contributes the cost of the nurse at the case conference. Eleven case conferences have been conducted, with the objective of process evaluation and refining the process. Multiple case conferences will then be conducted in one sitting on patients identified from the GP's list. Different means of conducting these conferences will be explored, including the use of telehealth. Finally a trial to test the efficacy of this process is proposed.

This project could be expanded to examine the elements of a patient-centred approach to palliative care based on a broader range of patients in Queensland Health. This would entail identifying the patients who are positive to the criteria mentioned above, within the public health system. It would also entail developing and implementing a plan that specifies roles for hospital-based services and community

based services including general practice. The plan would also specify how communication between the parts of the service could take place.

This outcomes of an in-depth pilot of this nature in one region could be applied to all Queensland health services. Since the BASIC-PC program is being developed at Ipswich, this could be a site for this work.

Palliative care in Aged care facilities

The proportion of the patients of aged care facilities in the Spanish trial that met the screening criteria of the Surprise question +2) +3), was 24% (6). In addition to the care issues set out above, the care is complicated by low staff to resident ratios, low numbers of trained Registered nurses and a reliance on staff trained to a level that prevents them from making clinical assessments, and problems with staff turnover. (Mitchell) Specific steps required to introduce palliative care principles, and care pathways for the very end of life are required. When implemented, emergency admissions to hospital dropped from 14% to 2% (22). However, ongoing effort is required to counter the loss of knowledge from staff turnover. This is particularly a problem in rural settings. Considerable effort in introducing this sort of care has been undertaken in Brisbane South under Liz Reymond (23).

General practitioners provide much of the medical care in nursing homes, but the proportion of GPs willing to care for residents in aged care settings is falling in line with the findings of Rhee (above). Specific strategies to encourage GPs to undertake work in aged care settings is required. Working with Medicare Locals may be a strategy to facilitate this. The Commonwealth did fund Aged Care panels in the old Divisions of General Practice organisations. Anecdotally these were very efficient ways of identifying local solutions to the provision of general practice services to aged care. They were disbanded around 2009, and no clear structure was developed to replace the role they played. Perhaps the use of nurse practitioners with a scope of practice in aged care may be a means of overcoming this problem.

In a district-wide palliative care program, planning for aged care palliative care would be part of the overall plan, and not separate. The rationale is the same as for outreach to general practice – better early planning should reduce overall system costs, including costs to Queensland Health.

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