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HEALTH AND COMMUNITY
SERVICES COMMITTEE

Submission 11

Mr Peter Dowling
Health and Community Services Committee
Parliament House
BRISBANE QLD 4000

Dear Mr Dowling

Inquiry into palliative care services and home and community care services in Queensland

I wish to extend my thanks to the Health and Community Services Committee for the opportunity to provide input for the *Inquiry into palliative care services and home and community care services in Queensland*.

It is with pleasure that I present the following submission concerning palliative care within Metro South Hospital and Health Service catchment area for consideration by the Health and Community Services Committee. The views expressed within this submission are mine alone and based on my experience in palliative care service provision.

Yours sincerely



Prof Liz Reymond MBBS (Hons), PhD, FRACGP, FACHPM

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HAWTHORNE QLD 4171

31st July 2012

Submission to Parliamentary Committee

Health and Community Services Committee

Inquiry into palliative care services and home and community care services in Queensland

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Inquiry into palliative care services and home and community care services in Queensland

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Section 1

Executive Summary

Introduction

This submission describes the specialist service capacity and future need for palliative care within the Metro South Hospital and Health Service (MSHHS) catchment area. It focuses on Metro South Palliative Care Services (MSPCS), highlighting innovations that enhance service effectiveness so that palliative patients receive the right care, at the right time, in the right place according to the patient's needs. It also focuses on measures that enhance sustainability and efficiency of the palliative care workforce into the future. It contextualises MSPCS within Australian Government Department of Health and Ageing national policies, including the National Palliative Care Strategy 2010 and the Queensland Government "Statement of Government Health Priorities".¹ Finally it addresses current gaps in palliative care service provision across MSHHS and Queensland in general and recommends strategies to address those gaps.

Capacity and future need for palliative care in MSHHS

MSHHS cares for a population of over a million people, one quarter of Queensland's population.² It is serviced by three Level 6 specialist palliative care services, including MSPCS.

It is difficult to quantify current specialist palliative care capacity and future need for palliative care within MSHHS, let alone across Queensland. Firstly, there is a lack of standardised data collection processes across generalist and specialist services and government and non-government services. Secondly, due to the rapidly changing dynamics of palliative care demand, old models used to predict future need are limited in relevancy.^{3,4} New models are needed that are inclusive of factors such as:

- a preference by most people to die at home⁵
- increasing proportion of fragmented family situations resulting in many frail sick elderly living alone with minimal support
- increased demand for palliative care services by the non-cancer population
- increasing acuity of people accessing palliative care
- an ageing population
- increasing numbers of demented and chronically ill residents living in aged care facilities with inadequate medical support
- a GP workforce that is corporatized, part-time and which makes fewer home visits while increasingly using deputising services for after-hours care
- the number of general, secondary, tertiary and quaternary hospitals in the catchment area of the palliative care service
- socio-demographic parameters of the catchment population.

Metro South Palliative Care Services (MSPCS) – effectiveness and efficiency

MSPCS functions to provide seamless, high quality, cost effective palliative care for those adults who need it, when they need it. The mission statement of MSPCS is twofold: to enhance living and ease the suffering of dying; and to be a leader in palliative care research and education.

Governance of the MSPCS sits within the Community and Primary Health Services, MSHHS and provides for in-reach services into all the MSHHS public hospitals, excluding Mater Hospital.

Innovations supporting the effectiveness of MSPCS that may be useful to other services include:

Dedicated palliative care units in public teaching hospitals. These units support seamless continuity of care for home based patients; if patients require admission they go directly to a bed (thus avoiding emergency departments) and are cared for by familiar staff under a single governance model. The units, while providing optimal care, encourage the development and sustainability of the palliative care workforce. In particular they allow junior rotating hospital staff to be exposed to the palliative care philosophy and palliative approach to care. Into the future this will translate into more people being involved in advance care planning, less futile and expensive procedures being carried out on frail and dying patients and more compassionate patient care at the end of life across hospital as well as community environments.

Residential Aged Care Facility (RACF) Service. RACFs are the hospices of today and likely to remain so into the future. Nonetheless there is professional consensus that people in RACFs frequently receive less than quality palliative care. In order to address this need MSPCS established a RACF palliative care service that in-reaches to 76 RACFs (some 98%) in MSHHS. This highly successful service is led by a Nurse Practitioner, Palliative Care RACF. The service has significantly reduced the number of inappropriate referrals and admissions of palliative RACF residents to emergency departments.⁶

Access for home-based palliative care equipment across MSHHS. MSPCS has established an affordable system that allows palliative patients, from any service in MSHHS, to access specialised palliative care equipment. The equipment is purchased by MSPCS and then stored, maintained and delivered to patients' homes by a contracted, independent private provider.

Specialised bereavement counsellors. Bereavement care is a cornerstone of quality palliative care.⁷ Nonetheless, there is a paucity of specialised palliative care bereavement counsellors in Queensland. MSPCS has been proactive in building its specialised bereavement care capacity.

Brisbane South Palliative Care Collaborative (BSPCC). The BSPCC is a unique innovation within Queensland specialist palliative care services that contributes to sustainable palliative care capacity building through the delivery of clinician recognised and driven priorities – a "bottom-up" approach to service planning and sustainability. It is a partnership between MSPCS, MSHHS and Griffith University School of Medicine. BSPCC aims to progress best practice community palliative care by implementing quality improvement projects, delivering evidence based palliative care education and training and developing intersectoral palliative care research programs.

Examples of the range of capacity building activities undertaken by BSPCC include:

- "National Implementation of the Palliative Approach Toolkit (PA Toolkit) for Residential Aged Care Facilities." Funded by Australian Government Department of Health and Ageing (in progress)
- "Enhancing access to palliative care for people living with advanced heart failure." Funded by Southside Partnership Council
- "Developing and Implementing a web-based Palliative Care Clinical Information Management System." Funded under the National Palliative Care Strategy

- “Development of the *Guidelines for the Handling of Medication in Community-Based Palliative Care Services in Queensland*.” Funded by BSPCC through monies obtained from fee for service education in rural Queensland
- “Palliative Care Capacity Building in Viet Nam.” Funded by CDC and PEPFAR
- “Lack of Benefit From Paracetamol (Acetaminophen) for Palliative Cancer Patients Requiring High-Dose Strong Opioids: A Randomized, Double-Blind, Placebo-Controlled, Crossover Trial”⁸ Funded by BSPCC through monies obtained from fee for service education in Queensland
- “A Palliative Approach for Staff in Aboriginal and Torres Strait Islander Aged Care Services – Introductory Workshops.” Funded by Palliative Care Australia.

Innovations that support the efficiency of MSPCS and that can be adapted for use by other services include:

Palliative Care Clinical Information System (PCCIMS). PCCIMS is a web-based information system and is the only one of its kind in Queensland. It allows for real time access to palliative patient information, thus improving patient safety and quality of care across all environments of care. PCCIMS promotes transitions to home care, ensures accessible, accurate and contemporaneous patient information while providing the ability to easily collect clinical activity data and meet jurisdictional and benchmarking reporting needs.

24 hour telephone on-call service. MSPCS has established a 24 hour telephone on-call service, staffed by rostered nurses and doctors, and enhanced by the existence of PCCIMS. This service ensures appropriate, adequate and safe care out of office hours and improves the confidence and security of family members to go the extra distance. Evaluation shows that it also decreases inappropriate presentations to emergency departments.

Access to emergency drugs. To facilitate patients remaining at home for as long as possible the MSPCS has a small stock of palliative care drugs that can be immediately provided to patients as required and that can tide them over whilst awaiting delivery of medications from their local pharmacist.

Caring safely at home resources. The likelihood of patients remaining symptomatically well managed at home often depends upon input from lay caregivers, mostly family members, who may be required to administer subcutaneous medications. MSPCS has produced a package of resources to educate and support carers to competently and safely draw up, store and administer subcutaneous injections, to monitor subcutaneous sites, to manage a medication administration record suitable for easy assessment by health professionals, and the uses of common medications used in palliative care. (This resource package has been rolled out to all community palliative care services in Victoria.)

Nurse Practitioners (NP). MSPCS has augmented its specialist workforce with the addition of two NPs in Palliative Care – one for RACFs and one for the community.

Clinical service delivery partnerships with other community service providers. MSPCS has multidisciplinary case conferences that include representatives from Anglicare, Blue Care, Silver Chain and Spiritus Domicillary Services. These conferences improve efficiency by promoting co-ordination of care, improving collaborative networking and encouraging standardisation of care.

Section 2

Recommendations

The following lists some important gaps in palliative care service provision across MSHHS, and Queensland in general, together with recommendations to fill those gaps.

Gap 1: Lack of adequately resourced specialist palliative care services (Level 5 or 6)* located, most appropriately, in the community and inclusive of in-reach services for hospitals and RACFs. Such services allow for seamless patient-centred care, provide for future workforce development and embed collaboration across generalist and specialist services. Community based services are in line with the findings that the majority of people prefer to be cared for at home, and that appropriate palliative care is best provided, not in acute facilities, but within the home setting.⁴

Recommendation 1: Depending on population needs and geographical constraints, establish at least one Level 5 or 6 Service in each local hospital and health service.

Gap 2: Absence of palliative care educator positions within Level 6 specialist palliative care services to ensure on-going education to generalists, specialists and the public within the catchment area of the specialist service.

Recommendation 2: Each Level 6 service is provided with funding to establish a recurrent educator position.

Gap 3: Need for telehealth partnerships linking Level 6 specialist palliative care services and regional and rural generalist services according to patient flow patterns, extending across hospital and health service boundaries where necessary.

Recommendation 3: Commission a study into the most effective and cost efficient way of establishing telehealth palliative care partnerships linking hospital and health services according to patient flows.

Gap 4: Paucity of NP specialist palliative care services for RACFs. NP in RACFs are cost effective in terms of changing the culture within aged care facilities, improving palliative resident care and reducing unnecessary and unwanted hospital admissions, investigations and treatments.

Recommendation 4: Each Level 6 service is funded to establish NP specialist palliative care services for RACFs within their catchment areas.

Gap 5: Lack of palliative care medication imprest systems for RACFs and standing orders to support symptom control in palliative residents.

Recommendation 5: Medicare Locals and Level 6 specialist palliative care services in partnership to establish palliative care medication imprest systems for RACFs and standing orders.

* Clinical Services Capability Framework, Version 3, Queensland Health 2011

Gap 6: Lack of after hours palliative care telephone on-call services. Such services are essential to support patients who choose to die at home and their families.

Recommendation 6: Medicare Locals and Level 6 specialist palliative care services in partnership to establish after hours palliative care telephone on-call services, inclusive of community based patients.

Gap 7: Insufficient specialist bereavement counsellors and bereavement services. There are very few specialist bereavement counsellors and services within Queensland, in contradiction to that recommended by PCA.

Recommendation 7: Hospital and health services provide adequate funding to ensure Level 6 specialist palliative care services employ adequate numbers of specialised bereavement counsellors.

Gap 8: Advance care planning. Specialist palliative care services need to be supported to continue building community awareness regarding the importance of advance care planning.

Recommendation 8: Medicare Locals and hospital and health services work in partnership to promote advance care planning to the wider community.

Gap 9: Insufficient availability of Home and Community Care (HACC) packages for palliative patients. These packages assist patients to stay at home in the final stages of life. Support needs to be available on a daily basis and for more hours in the day compared with many other people with chronic and frail conditions. Streamlining of packages, with rapid response times, could occur if Level 6 services were given block funding to tailor care packages brokered through domiciliary services rather than using ACAT.

Recommendation 9: That Metro South Hospital and Health Service trial the model whereby Level 6 services are provided with HACC and other community package funding to broker care packages for palliative care patients.

Gap 10: Volunteers. Volunteers are an important part of palliative care, they provide respite for carers and socialisation for patients. Further, volunteers help change societal attitudes towards death in the wider community.

Recommendation 10: Every level 6 service is funded for a trained volunteer co-ordinator position.

Section 3

Submission to Parliamentary Committee

Inquiry into palliative care services and home and community care services in Queensland

Introduction

This Submission

This submission concerns the specialist service capacity and future need for palliative care within the Metro South Hospital and Health Service (MSHHS) catchment area. It focuses on Metro South Palliative Care Services (MSPCS), highlighting innovations that enhance service effectiveness so that palliative patients receive the right care, at the right time, in the right place according to the patient's needs. It also focuses on measures that enhance sustainability and efficiency within the palliative care workforce into the future. It contextualises MSPCS within Australian Government Department of Health and Ageing national policies, including the National Palliative Care Strategy 2010 and the Queensland Government "Statement of Government Health Priorities"¹. Finally it addresses some immediate and important gaps in palliative care service provision across MSHHS and Queensland in general and recommends strategies to address those gaps.

Palliative Care and Society

Palliative care is the specialised holistic care of people who are suffering from a life-threatening illness. Historically, it developed from the recognition that dying patients needed better treatment that emphasised symptom control and truly patient-centred care addressing the psychological, social and spiritual needs of patients.

Today palliative care operates within a highly technologically driven healthcare system, where life can be maintained even in the absence of quality of life. This can create patient and family distress, clinical tensions and can generate unsustainable healthcare costs. Our society struggles to cope with conflicting challenges where, in spite of recognising human mortality, suffering is not tolerated and death can be viewed as a failure. Palliative care plays an important role in advocating for patients, families and healthcare systems to deal with these challenges, emphasising what is best for the individual patient within the overall context of their life. It is the core dimensions of care, compassion and humanity that are driving the increasing relevance of quality palliative care in modern healthcare delivery.

Society is always measured by our ability to show respect and care for the sick and dying. It is essential that palliative care is supported as an humanity based and cost efficient specialty that contributes to delivering the best answers for the health debates of the future.

Capacity and future need for palliative care within the MSHHS catchment area

The MSHHS covers an area of 3,856 square kilometres and includes a population of 1,038,090 – close to 25% of the total population of Queensland². In 2006 there were 4996 deaths in MSHHS.² It is estimated that in 2020 there will be 6403 deaths in MSHHS.⁹

In MSHHS there are three Level 6 specialist palliative care services (as defined by Queensland Health Clinical Services Capability Framework (CSCF) Version 3); St Vincent's Brisbane Hospital Tarmons Centre Palliative Care Service, the Mater Hospital Palliative Care Service and MSPCS. All services work to capacity. St Vincent's provides palliative care services to the state of Queensland; it is not limited to the MSHHS. It has a 30 bed in-patient unit linked to a 24 hour home-care service and accepts medical referrals from Brisbane and beyond. Mater Hospital Palliative Care Service has beds dispersed throughout the Mater Oncology Unit. It does not have a home visiting service. MSPCS is the main provider of public palliative care services in MSHHS. It is based in the community, providing a home visiting service and 24-hour telephone on-call service for residents within the catchment area of MSHHS and it services the six public hospitals (excluding Mater Hospital) of MSHHS. It has 2 dedicated beds at Beaudesert Hospital, an 8 bed in-patient unit at Logan Hospital, a 10 bed in-patient unit at QEII Hospital, and provides care, in collaboration with St Vincent's, for the 6 dedicated palliative care beds at Wynnum Hospital. All three Level 6 services provide out-patient clinics.

In terms of current MSHHS palliative care bed capacity, there are about 50 public beds. It is difficult to be more precise given the Mater service does not have a fixed number of beds and St Vincent's accepts public and private patients from beyond MSHHS. There is no accepted measure of community palliative care capacity. However, on 20/6/2012 the MSPCS had 453 community-based palliative patients, 162 of whom were residents of residential aged care facilities (RACFs).¹⁰ Certainly the demand for palliative care across MSHHS is increasing at a rapid rate. During the period June to November 2011 MSPCS had 1668 patients, and during the period December 2011 to May 2012 there were 2065 – an increase of some 30%.¹¹ During those two periods respectively 688 and 856 deaths occurred, the majority in hospitals.¹¹

Anecdotally all services in MSHHS report that they are unable to meet current demand for palliative care, and as stated in the Terms of Reference for this inquiry, significant increased need for services is expected into the future.

There are barriers that make it difficult to quantify current specialist palliative care capacity and future need for palliative care within MSHHS, as well as throughout Queensland. The first is a lack of standardised data collection processes across generalist and specialist services and government and non-government services. The second is that, due to the rapidly changing dynamics of palliative care demand, old models used to predict future need are limited in relevancy.^{3,4} New models are needed that are inclusive of contemporary factors such as:

- a preference by most people to die at home. According to a national poll conducted by PCA, nearly 75% of people would prefer to die at home.⁵
- Increasing proportion of fragmented family situations resulting in many frail sick elderly living alone with minimal support. This results in premature admissions to in-patient palliative care beds. Often, after the person's symptoms have been stabilised, they are still too sick to go home, but too well to remain in a "scarce" palliative care bed. This leads to

the most distressing situation where these people, in the last few weeks of their lives, have to undergo an Aged Care Assessment Team (ACAT) assessment and be transferred to a RACF. This inappropriate outcome generates enormous stress in patients and clinicians alike. Either slower stream palliative care beds are required or the palliative care capacity of RACFs needs to be greatly increased.

- increased demand for palliative care by the non-cancer population. On the basis of equity, such referrals are encouraged by MSPCS though the current non-malignant patient case load is only 30%.¹²
- increasing acuity of people accessing palliative care. As medical advances continue, by the time patients are referred to palliative care they often have complex and time consuming care needs. A snapshot audit on 17/7/12 revealed 35 patients, known to MSPCS, were in Princess Alexandra Hospital acute non-palliative care beds.¹³ Death is becoming a protracted business and this places increased pressure on already stretched services.
- an ageing population – people are living longer with chronic illness symptoms that impact their quality of life and that of their families.
- increasing numbers of demented and chronically ill residents living in RACFs with inadequate medical support. It is widely acknowledged that few general practitioners (GPs) visit RACFs and that residents of RACFs are disadvantaged with respect to palliative care. Staff of RACFs are under-skilled and under-educated in palliative care, and the poor registered nurse to resident ratios makes it difficult for residents to receive breakthrough narcotic pain relief when required. Education and staffing are the most important barriers to providing effective palliative care in RACFs.
- a GP workforce that is corporatized, part-time and which makes fewer home visits while increasingly using deputising services for after-hours care. GP practice is geared progressively towards providing episodic care in short surgery-based consultations. Such practice is a significant barrier to providing effective palliative care as it is not conducive to the provision of holistic palliative care and impacts many people's preferred option of dying at home. In areas of MSHHS it can be difficult on the weekend to get GPs to home visit to issue life extinct or death certificates, as a consequence the police are usually called and an expected death can become a coroner's case. This is particularly distressing for families.
- the number of general, secondary, tertiary and quaternary hospitals in the catchment area of the palliative care service – hospitals attract morbidity and mortality.
- socio-demographic parameters of the catchment population. For instance, about 2% of the MSHHS community identify as Aboriginal and/or Torres Strait Islander and 25% of the population was born overseas. MSPCS cares for one of the most culturally and linguistically diverse populations in Queensland.² This presents enormous challenges for palliative care services that cross ethical, cultural, medico-legal and social domains. The monetary cost alone to obtain appropriate and robust interpreters is significant.

Considering the above it is clear that the numbers of dedicated palliative care beds in MSHHS, and across Queensland, need to increase. These extra beds do not necessarily need to be in acute care hospitals, but they need to be adequately resourced and staffed. Indeed, they could be in slow stream units within sub-acute facilities (such as Canossa Private Hospital), or bed equivalents, share cared with GPs, to provide high quality community care. For non-hospital care to be effective, community palliative care resources, especially within RACFs, need to be extended in the future. Finally the belief that GPs are well positioned to provide the majority of end of life care in the community should be re-visited. Specialist palliative care services should be

resourced to up-skill, consult and share care with those GPs who are interested in palliative care and fill the gap in care left by GPs who do not wish to care for dying patients.

Metro South Palliative Care Services (MSPCS) – effectiveness and efficiency

Introduction to MSPCS

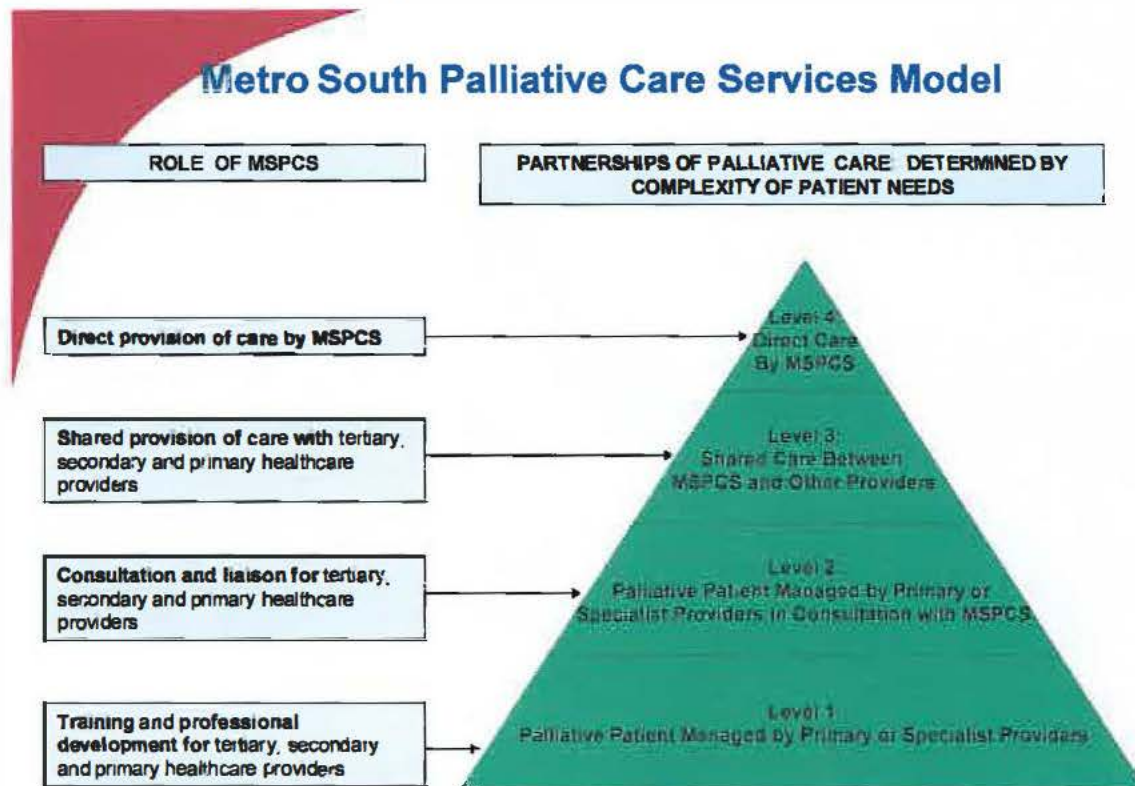
MSPCS functions to provide seamless, high quality, cost effective palliative care for those adults who need it, when they need it. The mission statement of MSPCS is twofold:

- To enhance living and ease the suffering of dying.
- To be a leader in palliative care research and education.

Governance of the MSPCS sits within the Community and Primary Health Services, MSHHS and provides for in-reach in-patient units and consultatory services into all the MSHHS public hospitals, with the exception of Mater.

The MSPCS model of care is adapted from the population-based approach to palliative care service provision espoused by PCA, 1995.¹⁴ It recognises differences in the complexity of palliative patients' needs and encompasses the clinical and workforce development responsibilities of a Level 6 specialist service. The model is depicted in the figure below – the higher the level in the triangle the greater the complexity of the patients' care needs. The model encompasses consultatory (for GPs or other medical consultants), shared-care or direct care for patients throughout MSHHS.

Figure 1: MSPCS Model of Care



Effectiveness

There is limited evidence concerning the effectiveness of palliative care services. One way of measuring effectiveness is through the use of clinical indicators. As palliative care is a relatively new medical specialty there is little consensus concerning what constitutes quality clinical indicators for palliative care, though the Australian and New Zealand Society for Palliative Medicine (ANZSPM), PCA National Standards Assessment Program (NSAP) and Palliative Care Outcomes Collaboration (PCOC) are all working in this area. Given the absence of these indicators, reasonable measures of effectiveness can be gauged by whether patients receive the right care, at the right time and in the right place.¹⁵

1. **Right care.** The right care, or appropriate care, is generally considered to be care that is in line with evidence-based or consensus-based guidelines delivered in accordance with standards prescribed by the peak body of the specialty. PCA is the peak body of palliative care in Australia and it has documented "The Standards for Providing Quality Palliative Care for all Australians"¹⁶. MSPCS uses these Standards and relevant guidelines to inform practice and also to evaluate the quality of services provided. MSPCS provides holistic care that respects patient choice (advance care planning), is focussed on the relief of physical, psychosocial and spiritual suffering and that extends to the needs of the family. To sustain the right care MSPCS develops standardised clinical tools (e.g. Residential Aged Care End of Life Care Pathway), is accredited to train palliative care registrars and practices in collaborative partnerships with other generalist and specialist healthcare providers.
2. **Right time.** The right time for care is determined by the patient's needs. Eighty-five percent of patients, triaged as urgent by referring doctors, are contacted or seen by MSPCS within 24 hours.¹⁷ (It needs to be acknowledged that MSPCS is an urban service and so does not have to contend with the geographical barriers faced by regional and remote palliative care providers when servicing their patients.)
3. **Right place.** Progressively more emphasis is being placed on patients being able to die in their place of choice. In MSPCS, between 2011 and 2012, 97% of patients who indicated that they wanted to die in their RACF achieved that outcome. Similarly 80% of people who wanted to die in hospital were able to, as were 74% who wanted to die in a dedicated palliative care bed. However only 56% of people who wished to die at home achieved that goal¹⁸ – this result is almost definitely due to a lack of community palliative care staff.

Clearly MSPCS provides effective care. Some of the innovations that have allowed this to be achieved include:

Dedicated palliative care units in public teaching hospitals

The Productivity Commission "Inquiry into Caring for Older Australians", the National Health and Hospitals Reform Commission "A Healthier Future for all Australians" and the Australian Government Department of Health and Ageing "Living Longer. Living Better. Aged Care Reform Package April 2012" reports all recognise that Australia's palliative care needs are not being met by current arrangements.

Currently most palliative care units are isolated from main stream medicine. MSPCS, under the governance of the Community and Primary Health Services, MSHHS, has established two in-patient palliative care units in public hospitals, staffed by specialist community palliative care professionals. These units support continuity of care for home based patients; if patients require admission they go directly to a bed (thus avoiding emergency departments) and are cared for by familiar staff under a single clinical governance model. The units, while providing optimal care, encourage the development and sustainability of the palliative care workforce. In particular they allow junior rotating hospital staff (across all disciplines involved in palliative care) to be exposed to the palliative care philosophy and palliative approach to care. Into the future this will translate into more people being involved in advance care planning, less futile and expensive procedures being carried out on frail and dying patients and more compassionate patient centred care at the end of life across hospital as well as community environments.

MSPCS model that facilitates continuity of care

MSPCS has a multidisciplinary team that operates across the patient continuum of care including hospital, dedicated palliative care in-patient units, home, outpatient settings and residential and aged care facilities. Such a model, supported by a patient electronic record, allows for seamless, specialised and standardised care usually in the patient's environment of choice. This continuity builds relationships and generates trust and security for the vulnerable patient/family unit of care. Patients and families are not confused about who is providing care and they are provided with consistent information rather than conflicting views regarding prognosis, which can lead to false expectations and complicated grief for surviving family members.

Residential Aged Care Facility (RACF) service

RACFs are the hospices of today and likely to remain so into the future; nonetheless there is professional consensus that people in RACFs frequently receive less than quality palliative care.⁶ To help rectify this situation MSPCS has established a RACF palliative care service that in-reaches to 76 RACFs (some 98%) in MSHHS. This innovative and highly successful service is led by a Nurse Practitioner, Palliative Care RACF supported by registered nurses, registrars and consultants. The service provides consultatory and shared care, education and research associated with quality improvements in RACF care. This service has significantly reduced the number of inappropriate referrals and admissions of palliative RACF residents to emergency departments.⁶

Education

One of the major barriers to the delivery of quality palliative care is lack of funding for Level 6 services to employ clinical educators. MSPCS recognises the need to provide education services for all professions within community primary palliative care - both through opportunistic encounters with individual patients but importantly also through a more structured approach to education and up-skilling. On-going education sessions, accredited with the Royal Australian College of General Practitioners (RACGP) for continuing professional development and the Royal College of Nursing Australia (RCNA) for continuing nursing education are offered by MSPCS as resources permit. However, more needs to be done. Local education by specialist clinicians leads to improved collaboration between specialist and generalist services and improves networking between clinicians.

Access for home-based palliative care equipment across MSHHS

MSPCS has established an economical, equitable system that allows palliative patients, from any service in MSHHS, to access specialised palliative care equipment when required. MSPCS purchased a variety of commonly used equipment (e.g. hospital beds) that is stored, maintained and delivered to patients' homes, set-up, collected and cleaned by an independent private provider. Large/expensive items are funded directly by MSPCS, while smaller items are funded partially by the patient/family.

Specialised Bereavement Counsellors

Bereavement care is a cornerstone of quality palliative care.⁷ Nonetheless, there is a paucity of specialised palliative care bereavement counsellors in Queensland Health palliative care services in particular. Research from intensive care specialists shows that family members often exhibit signs of post traumatic stress disorder (PTSD) particularly when patients die in intensive care units and the family member has been involved in end of life decision making.¹⁹ While similar research has not been completed in palliative care this is likely to be the case for members of palliative patients' families, as the outcome for palliative patients is always death and family members are routinely involved in end of life decision making. To improve outcomes for bereaved families, including future morbidity, increased numbers of specialist qualified bereavement counsellors are required.

MSPCS has been proactive in building its bereavement care capacity and currently employs 2.2 full time equivalent specialist bereavement counsellors.

Brisbane South Palliative Care Collaborative (BSPCC)

The BSPCC is a unique innovation within Queensland specialist palliative care services that contributes to sustainable palliative care capacity building through the delivery of clinician recognised and driven priorities – a “bottom-up” approach to service planning and sustainability. It is a partnership between MSPCS, MSH and Griffith University School of Medicine. BSPCC aims to progress best practice community palliative care by implementing quality improvement projects, delivering evidence based palliative care education and training and developing intersectoral palliative care research programs.

Examples of the range of capacity building activities undertaken by BSPCC include:

- “National Implementation of the Palliative Approach Toolkit (PA Toolkit) for Residential Aged Care Facilities.” Funded by Australian Government Department of Health and Ageing (in progress)
- “Enhancing access to palliative care for people living with advanced heart failure” Funded by Southside Partnership Council
- “Developing and Implementing a web-based Palliative Care Clinical Information Management System.” Funded by the National Palliative Care Strategy
- “Development of the *Guidelines for the Handling of Medication in Community-Based Palliative Care Services in Queensland*” Funded by BSPCC through monies obtained from fee for service education in rural Queensland
- “Caring Safely at Home. Supporting Carers of People Requiring Palliative Care at Home”. Funded by Department of Health and Ageing

- "Palliative Care Capacity Building in Viet Nam." Funded by CDC and PEPFAR
- "A randomised controlled trial investigating possible additive analgesic effects of paracetamol in palliative patients using high-dose strong opioids."⁸ Funded by BSPCC through monies obtained from fee for service education in Queensland
- "A Palliative Approach for Staff in Aboriginal and Torres Strait Islander Aged Care Services – Introductory Workshops." Funded by Palliative Care Australia.

The inclusion of such collaboratives in other specialist palliative care services would have obvious advantages for the Queensland population and the specialty of palliative care.

Efficiency

The efficiency of MSPCS is evidenced by the fact that in the past six months 2065 palliative patients have been appropriately cared for by a multidisciplinary team of fewer than 40 full time equivalent staff across the geography of the MSHHS catchment area.²⁰ This efficiency ensures value for taxpayer dollars.¹ Innovations to achieve efficiency include:

Palliative Care Clinical Information Management System (PCCIMS)

PCCIMS is a web-based information system and is the only one of its kind in Queensland. It allows for real time access to palliative patient information, thus improving patient safety and quality of care across all environments of care. PCCIMS promotes transitions to home care, ensures accessible, accurate and contemporaneous patient information while providing the ability to easily collect clinical activity data and meet jurisdictional and benchmarking reporting needs. It is particularly important for clinicians who are on-call when receiving after hours telephone calls from patients' families as they are able to optimise symptom management by accessing patient notes and checking medications, thus increasing safety of care and reducing presentations to emergency departments and avoiding admissions to acute care beds. An information system that collects both patient and activity data overcomes the potential for double entry of information which is clinically frustrating as it leads to less time for patient care.

24 hour telephone on-call service

MSPCS has established a 24 hour telephone on-call service, staffed by rostered nurses and doctors and enhanced by the existence of PCCIMS, to support patients, families and other clinicians across the care continuum. This service ensures appropriate, adequate and safe care out of office hours and improves the confidence and security of family members to go the extra distance. Family members frequently comment on the comfort that they gain knowing that they can talk to staff they know and trust when feeling unsure about caring options. Evaluation shows that it also decreases inappropriate presentations to emergency departments.

Access to emergency drugs

Palliative care patients are inherently unstable and symptoms can emerge at any time and need to be treated, often pharmacologically. Community pharmacies do not always stock medications prescribed by specialist palliative care doctors. To facilitate patients remaining at home for as long as possible the MSPCS has a small stock of palliative care drugs that can be immediately provided to patients as required and that can tide them over whilst awaiting delivery of medications from their local pharmacist.

Caring safely at home resources

The likelihood of patients remaining symptomatically well managed at home often depends upon input from lay caregivers, mostly family members, who may be required to administer subcutaneous medications. Brisbane bereaved carers report their ability to provide injections adds value to patient care; nonetheless many report the need for education and resources to assist them in this quasi-professional role. MSPCS has produced a package of resources to educate and support carers to competently and safely draw up, store and administer subcutaneous injections, to monitor subcutaneous sites, to manage a medication administration record suitable for easy assessment by health professionals, and to show the uses of common medications used in palliative care. (This resource package has been rolled out to all community palliative care services in Victoria.)

Nurse Practitioners (NP)

There is a significant gap between the current and ideal workforce numbers in palliative care.²¹ In MSHHS some of the medical workforce gap has been filled by the addition of two NPs in palliative care – one for RACFs and one for the community, particularly in the Beaudesert and Moreton Bay Island areas.

Clinical service delivery partnerships with other community service providers

MSPCS has multidisciplinary case conferences that include representatives from Blue Care, Silver Chain and Spiritus Domicillary Services. These conferences improve efficiency because they promote co-ordination of care, improve collaborative networking and encourage standardisation of care.

Some of the effectiveness and efficiency measures described above are likely to be found in other specialist services – if not, they could certainly be generalised to other models of local care across Queensland.

Gaps in palliative care service provision across Queensland, inclusive of MSHHS

The relative neglect of palliative care service provision in Queensland needs urgent revision. The following outlines some of the more immediately important gaps in service provision across Queensland, summarises positive consequences of filling those gaps and makes recommendations to fill the gap.

Gap 1: Lack of adequately resourced specialist palliative care services (Level 5 or 6, CSCF Version 3) located, most appropriately, in the community and inclusive of in-reach services for hospitals and RACFs.

Two examples of such services include MSPCS and the St Vincent's Palliative Care Service. Advantages of such services:

- Community based services are in line with the findings that the majority of people prefer to be cared for at home, and that appropriate palliative care is best provided, not in acute facilities, but within the home setting.⁴

- A single clinical governance structure that crosses environments of care promotes seamless patient care – right care, right place and right time
- Meets immediate demand and provides infrastructure upon which to build sustainable services to meet future demand. This is particularly relevant when the unit is associated with a public teaching hospital (e.g. MSPCS beds in QEII Hospital)
- Provides opportunities for specialist workforce development e.g. medical training registrars, nurse practitioners and specialised allied health workers in palliative care as well as appropriate environments for student placements
- Provides opportunity for the specialist and generalist workforce to embed collaborative clinical networks utilising standardised models of care with shared documentation processes and jurisdictional data collection procedures.

Recommendation 1: Depending on population needs and geographical constraints, establish at least one Level 5 or 6 service in each Local Hospital and Health Service.

Gap 2: Absence of palliative care educator positions within Level 6 specialist palliative care services to ensure ongoing education to generalists, specialists and the public within the catchment area of the specialist service. These positions need to be dedicated for education; clinical staff cannot simply be expected to add education to their already crowded clinical duties. No such positions are currently funded. Advantages:

- A cheap investment for significant gain.
- Provides a mechanism to educate the public about the importance of advance care planning.
- While all dying people can be advantaged by a palliative approach to care, not all require direct palliative care from a specialist service and indeed, many people prefer to be cared for at home by generalist community providers, such as HACC and Medicare Local staff. These staff need education and training to provide best practice palliative care.
- A specialist palliative care education officer increases the capacity and sustainability of primary community care providers to deliver quality care at the end of life. Such education is best provided in formal structured sessions e.g. GP accredited continued professional development (CPD) courses.
- Some education can attract funding for the service, dependent upon the model of service delivery.

Recommendation 2: Each Level 6 service is provided with funding to establish a recurrent educator position.

Gap 3: Need for telehealth partnerships linking Level 6 specialist palliative care services and regional and rural generalist services according to patient flow patterns, extending across hospital and health service boundaries where necessary. Advantages:

- These partnerships add to palliative care capacity in rural and remote communities
- Improve discharge planning and quality of care for patients returning home
- Improve equity of access for rural patients.

Recommendation 3: Commission a study into the most effective and cost efficient way of establishing telehealth palliative care partnerships linking hospital and health services according to patient flows.

Gap 4: Paucity of NP specialist palliative care services for RACFs. NP in RACFs are cost effective in terms of changing the culture within aged care facilities, improving palliative resident care and reducing unnecessary and unwanted hospital admissions, investigations and treatments.

Recommendation 4: Each Level 6 service to establish NP specialist palliative care services for RACFs within their catchment areas.

Gap 5: Lack of palliative care medication imprest systems for RACFs and standing orders to support symptom control in palliative residents. Advantages:

- Allows for immediate symptom control for residents, until GPs can provide prescriptions
- Decreases transfers to acute care facilities
- Improves quality of life and death for RACF residents.

Recommendation 5: Medicare Locals and Level 6 specialist palliative care services in partnership to establish palliative care medication imprest systems for RACFs and standing orders.

Gap 6: Lack of after hours palliative care telephone on-call services. Such services are essential to support patients who choose to die at home and their families.

Recommendation 6: Medicare Locals and Level 6 specialist palliative care services in partnership to establish after hours palliative care telephone on-call services, inclusive of community based patients.

Gap 7: Insufficient specialist bereavement counsellors and bereavement services. There are very few specialist bereavement counsellors and services within Queensland, in contradiction to that recommended by PCA.

- Specialised bereavement counsellors optimise outcomes for grieving patients
- Specialised bereavement counsellors assess family members at risk of complicated bereavement and can implement interventions to care for family members after a death.

Recommendation 7: Hospital and health services provide adequate funding to ensure Level 6 services employ adequate numbers of specialised bereavement counsellors.

Gap 8: Advance care planning. Specialist palliative care services need to be supported to continue building community awareness regarding the importance of advance care planning.

Recommendation 8: Medicare Locals and hospital and health services work in partnership to promote advance care planning to the wider community.

Gap 9: Insufficient availability of HACC care packages for palliative patients. As a result of under resourcing, there can be tension between HACC programs and palliative care services because palliative care patients can be denied access to HACC programs. These packages can assist patients to stay at home in the final stages of life. Support needs to be available on a daily basis and for more hours in the day compared with many other people with chronic and frail conditions.

Streamlining of packages, with rapid response times, could occur if Level 6 services were given block funding to tailor care packages brokered through domiciliary services rather than using ACAT.

Recommendation 9: That Metro South Hospital and Health Service trials the model whereby Level 6 services are provided with HACCC and other community package funding to broker care packages for palliative care patients.

Gap 10: Volunteers. Specialist palliative care services need paid and trained volunteer co-ordinators. Volunteers are an important part of palliative care, they provide respite for carers and socialisation for patients. Further, volunteers help change societal attitudes towards death in the wider community.

Recommendation 10: Every Level 6 service is funded for a trained volunteer co-ordinator position.

Section 4

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