CONTINUITY OF CARE: PALLIATIVE CARE IN THE COMMUNITY

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Abstract

The majority of people living with a life-limiting illness spend most of their time in the community and would prefer to die at home. General practitioners and generic community nursing service are the lynchpins of primary care. The effectiveness of the interdisciplinary palliative care team has been well demonstrated. What are the challenges for people living with a life-limiting illness when changing sites of care, and what are the difficulties in providing care in the community? How do primary care and specialist teams interface? There are differing models of care. Mechanisms to foster relationships of respect and trust, and to facilitate effective communication are vital if optimal coordinated community care for people living with a life-limiting illness is to occur.

Introduction

One of the aims of palliative care is to facilitate “seamless care”, however reality may not always mirror rhetoric. What are the challenges for people living with a life-limiting illness when changing sites of care, and what are the difficulties in providing timely, supportive care in the community that is sustainable, appropriate and not duplicating or disempowering of existing services?

Primary care

In Australia, the general practitioner and the generic community nursing service are the lynchpins of primary care. There is, however, no formal contract between family doctors and patients. Medical registration boards have requirements that adequate after-hours provisions are made and there are incentives for family doctors to offer after hours and home visiting services. However, there is insufficient financial incentive for prolonged consultations – often needed by the person living with a life-limiting illness or for house calls. Until quite recently funders have not recognised the time and skills required to coordinate care. Enhanced primary care reimbursement items were introduced by the Health Insurance Commission in 1999; however Australian general practitioners have been slow to embrace these – partly perhaps because of their apparent bureaucratic complexity.

General practitioners are community-based, may have a long-standing relationship with the patient and can be ideally placed to offer care from before diagnosis, continuing to prolonged bereavement support for the family. They are likely to be more accessible, visible and approachable. There are, however, many competing demands on general practitioner time. The provision of a sustainable service that meets the needs of patients, balances the many demands on the doctor’s time and provides the practitioner with adequate personal time is a very large challenge. And considering that the average general practitioner is likely to care for only five patients per year who might die with a protracted illness, it is not surprising that problems of skill maintenance and inadequate access to community resources are well-recognised issues. Access to home-visits and after-hours care are concerns for families. And perceived or real delays in diagnosis may also cloud the trust of the therapeutic relationship with the general practitioner.

The majority of people living with a life-limiting illness spend most of their time in the community. Most people when asked would prefer to die at home, however there are challenges and burdens associated with home care. There is the need for increasing support and supervision: the need for a carer. There are the physical difficulties for the patient and the carer. Emotional needs and anxieties about medications and changes in physical condition are real concerns, as are fears about the time of death. Death at home may not be possible or even preferable. Even if death does not occur at home, over 90% of the last year of life is spent at home and in the community.

Specialist palliative care teams

Specialist community palliative care teams have grown as a natural extension of in-patient hospice facilities. In countries including the United Kingdom, Canada and Australia there are interdisciplinary teams of specialist palliative care practitioners working to support people with life-limiting illnesses. Hearn and Higginson have demonstrated improved patient and carer satisfaction when specialist palliative care teams are involved. More patient and family needs are identified and dealt with, time in acute hospitals is reduced and costs of overall care are reduced.

Unlike the United Kingdom, in Australia, palliative care services have developed mainly within mainstream health services. However, service provision is still quite patchy. Rural and remote areas are generally poorly served. There is a scarcity of access to proximate specialist medical assessment and advice, and even access to specialist palliative nursing expertise is limited. Specialist psychological and allied health care is even more scarce. Major cities are generally better served but there are areas of specific need and inequities in access to services.

There is a dearth of high quality research into specialist models of palliative care and its impact on consumer satisfaction. Almost all has occurred in the United Kingdom and is not necessarily transferable to Australia, especially considering the significantly different models of general practice. Evidence of improved continuity of care provision by teams in other areas of health care is available, but inferences cannot be safely made.

Hospital services

Hospital services frequently may see their care as central. Medical and radiation oncologists, surgeons and other involved physicians may request continuing follow-up consultations when active therapies have ceased. The intention may be to provide support and surveillance, and to avoid a sense of abandonment for the patient. This may also be easier than closing the relationship, dealing with what this means for the patient and family, and facilitating a referral to a palliative care service. Even better would be an earlier introduction to palliative services, collaborative care and continuing involvement by the general practitioner. Continuing oncology reviews may give subliminal messages of hope for further treatment options or even cure, when all avenues have been explored. However the
complexity of modern treatments may mean that some general practitioners may have difficulties in being able to provide current and comprehensive care coordination.

The interface

So, what is the interface between primary care and specialist teams? And if care is to be coordinated, by whom?

These are not easy questions and opinions and solutions will vary. The full spectrum of models of care exists. There are palliative care services that take over all medical and nursing services, and models that are entirely consultative, only accepting referrals with the general practitioner's consent and contracted support in-hours and after-hours. There are general practitioners who expect and are the sole medical expertise for their patients in the community, controlling all external referrals and service provisions.

Use of language such as “case manager” is not uncommon within some palliative care teams, domiciliary services and generic nursing agencies, yet do they really mean and provide this? Or are general practitioners the “gatekeepers to care” or might this role reside with another specialist doctor or even another professional?

Team care in the community has been demonstrated to reduce overall costs, reduce time spent in the acute hospital setting, to meet more patient and family needs and to be rated as highly satisfactory by consumers. The challenge is to assess the strengths and weaknesses of the specific primary care resources, the specialist palliative care team and available service agencies and to work together.

Sensible use of available resources within and outside of the team is important. Models of care may risk being designed to meet provider staffing rather than consumer needs. Rather than gate-keeping or case-management, if care is to be coordinated, there needs to be an overview. Different issues and aspects of care will involve different professionals or members of the team. Yet issues of professional responsibility cannot be avoided by arguments of “team decision-making.” There is a need for flexibility in care planning.

General practitioners and community nurses will continue to provide the greater part of care for patients. All need exposure to the philosophy, knowledge and skills that specialist palliative care has to offer. Palliative care has a social responsibility to continue educating all groups of health professionals and the general public. And if resources or practitioner attitudes or skills are lacking to actively work for change.

Primary carers may need to be taught how to work in a team and roles and responsibilities will need to be explored. The challenge for specialist teams is to support primary carers collaboratively, ensuring that patients receive optimal care; modeling good behaviours and allowing the acquisition of new knowledge and skills in a safe environment.

A challenge for the family doctor is to prepare the patient and family for a palliative focus and supports. Ideally this might be promoted at diagnosis or relapse as one part of the care package. To know when it is the “right time” to make a referral may not always be apparent. Facilitatingcordial relationships with an interdisciplinary palliative care team should assist informal discussions about possible referrals, to explore what additional value the team might be able to provide to the current situation.

General practitioners may need to find a way of expressing their view of the clinical scenario and for feeding back their reactions and assessments to the team. Difficulties with the specialist team from the primary care perspective may not be frequently expressed or heard. The general practitioner may need to be active in demonstrating their preparedness to provide not only reactive care, but to adopt a more supervisory stance – to schedule regular review. Teams may need to learn the strengths of nurturing, interfacing and trusting general practitioners.

Communication is a core requirement. This begins with a dialogue at referral to set guidelines and to explore specific issues and needs. A well-constructed formal summary of the assessment is a valuable basis for collaborative care; not an exhaustive document that is in reality a summary for the specialist practitioner’s own records. This responsibility is not only from specialist to general practitioner. Primary carers need to be aware of their mutual obligation for communication and to have developed systems to facilitate this. Teams should try to develop some continuity in who interfaces with a specific primary carer, to assist in developing predictable contacts for primary carers and to allow relationships to develop.

The essence for team members is to foster not only relationships of respect and trust within the specialist team, but also with the hospital communities and primary care practitioners with whom they interact. Clear plans for assessment, review and after-hours support need to be made. And the highest priority and greatest challenge for all providers is effective, succinct, timely mutual communication.

References