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Executive summary

As people face a life-limiting illness, they are clear about their needs and expectations. People want to focus on relationships and legacy issues, and the care that is provided must support people at the end of life in these key areas. The care that is provided at this time of life has consequences not only for the person who is dying, but also for their families and friends at the time and subsequently.

Australia provides excellent palliative care that is, overall by international standards, well integrated into the provision of health care. There is a trained workforce that has been built up over the last quarter of a century, to complement the role that every health professional has in providing care for people at the end of life.

There have been several key national initiatives funded by the Commonwealth to improve systematically the care that is offered. These programs are having a positive impact. Most notably, benchmarking is helping to improve symptom outcomes for people at the end of life. In research and teaching, Australia contributes strongly internationally.

Despite these excellent initiatives and improving outcomes, there are opportunities for systematic improvements.

People with diagnoses other than cancer are under-represented in those seen by specialist palliative care services, despite having similar needs at the end of life.

Services should adopt a needs-based approach to assess people referred to ensure those with the most complex needs are prioritised to receive limited resources.

There are opportunities and a necessity to more effectively engage primary care, especially general practitioners. The funded mechanism for this is through case conferencing, which has been shown to improve significantly the provision of care.

Long term carer outcomes need to be assessed as a result of providing care for someone at the end of life, for a period of years after their role has been completed. A key measure of success of good palliative care should be the health and wellbeing of caregivers in the years after having relinquished the role.

What people want as they live with a life-limiting illness

It is easy to assume that we would all know what we want and how we would each prioritise our time if we were faced with a life-limiting illness. It is necessary to ask the right people at the right time of life 'What is important?' To do this, one must ask people facing the end of life, not simply people who are well. The answers differ from the expectations that many people who are well would have.

Steinhauser and her team asked a random sample of people with advanced cancer what was important to them as they faced the likelihood of death within months. [1] At the same time doctors, other health professionals and caregivers who had provided care for someone at the end of life were also asked. Areas where there was agreement between all four groups included pain and symptom control as the number one priority. The next four priorities were not physical: preparation for death (knowing what to expect; financial and family issues being settled, being prepared), achieving a sense of completion (saying goodbye, legacy issues), being involved in decision making preferences and being treated as a whole person. Areas where people facing death put emphasis not seen in the other three groups included maintaining a sense of humour, not being a burden to family and friends, being mentally alert (even at the cost of poorer symptom control) and *not* being concerned about the actual place of death. (It needs to be noted that some people actively choose not to die at home for a number of relevant reasons. For some people, dying in a hospital or hospice is an active choice, not a failure of the health system to provide adequate care.) Individual preferences will differ, but this gives an overview of key areas that should underpin a systems-wide approach to providing and improving care.

Ultimately, good palliative care is about the active management of anything that reduces comfort or function in key areas of personhood in the face of a life-limiting illness: physical, social, emotional, sexual, or existential domains. It is the ability to function as well and as independently for as long as possible. These are therefore the goals that underpin the planning and delivery of good palliative care.

Caregivers

Reliance on caregivers

There is a massive reliance on caregivers to provide care in the community. There are clearly large numbers of unmet needs for those carers and often very limited support. Direct focus on caregiver education and support is very limited, and yet the health and social systems assume that this care will be in place and will continue to be delivered. Caregiving is an enormous challenge and for most, it is one of life's major events.

There is a very high incidence of caring for someone at the end of life in our society. From population data, one in every three people will have had someone close to them die from an expected death in the last five years with one in ten people providing care in these

circumstances. Most notably, one in thirty people across the community provided day-to-day hands-on care for someone at the end of life in the last five years. Attention to the needs of caregivers while in the role and having relinquished the role is crucial if optimal care is to be offered. A key measure of success of good palliative care should be the health and wellbeing of caregivers in the years after having relinquished the role.

At a policy level, every time the statement is made that the rates of home deaths should increase, there is the challenge of how caregivers are going to be able to deliver that care with little real help or support. Although there is a great deal of discussion about cost shifting in health care, the ultimate cost shifting is to move the financial burden of end of life care to families and friends. The costs borne by families and friends need to be factored into discussions about place of care including place of care at the time of death. Often, with little training or support, they provide extraordinary care. With increasing complexity of care delivered outside of hospitals, it is simply expected that the additional care will be taken on by this huge and largely unrecognised workforce.

Let's not romanticise the role

Although providing care for someone close at the end of life may be a huge opportunity for personal growth and development, it can also be one of the most challenging and daunting things ever asked of any of us. In a review commissioned by the Department of Health and Ageing, former caregivers spoke frankly about how challenging the role was for many of them. [2] In population data, one in four caregivers is undecided or would definitely not provide care again having provided care for someone at the end of life. [3] The system has yet to come to terms with the impact of this figure in the coming decades. This also supposes that the person with the life-limiting illness and their caregivers will always agree about the place of care. Although few studies have addressed this, Australian data suggests that these views will be discrepant at times, and choices may change over time. [4] These differences will either impact on place of care, the wellbeing of caregivers, or both.

Inherently, what is asked of a caregiver for someone at the end of life may or may not be what is needed by either the person who is dying or their friend / relative. There are only so many hats one can wear simultaneously. Is it more important to be friend / confidant / lover or nurse / cleaner / laundry expert / cook? For each person, the answer is likely to be different, and the answer may change as time passes for that particular person.

Initiatives to support caregivers more effectively

One Australian study looked at assessing the needs of caregivers specifically, separately to the other patient-centred assessments. [5] The process included a focus on the previous experiences of the caregiver, their network of support and whether there were other supports that could be mobilised or organised in a more meaningful way. The correlate was that many friends and family want to help and are often not sure what will be most useful.

By having a broker or facilitator to help with these conversations, key opportunities can be identified that better support caregivers and mobilise the energy, love and commitment of a far wider circle of people.

Definitions (including needs-based care)

Definition

Palliative care is the active care of people with life limiting illnesses, focusing on optimising comfort and function from the time it is recognised that the person has a progressive disease that will lead to their death. It happens in parallel with other care including disease modifying treatments as appropriate. It is not a matter of choosing either disease modifying treatment or palliative care.

Application of definitions in government policy

Within the Australian context no Federal Government processes limit the access to palliative and supportive services by prognosis or by diagnosis. The one exception to this is the carer's allowance which asks for life expectancy to be estimated and written down on an application that is then handed back to the caregiver and potentially the person with the life-limiting illness. **This should be changed.** It is almost certain that this is a significant barrier to the use of this resource and is causing needless financial hardship.

Definitional issues – palliative approach versus specialised palliative care

Palliative Care Australia in policy documents make a distinction between a *palliative approach* (a set of competencies that every single clinician - doctor, nurse, allied health practitioner- should have and be able to adequately use when necessary from the time of completing training) and *specialised palliative care* that is the process of providing care for people with more complex needs as well as developing the research and educational resources required to improve care across the community.

Population prevalence of needs

At a community level, the need for palliative care is going to grow not simply because of the increasing number of people in the community but because the way we experience death continues to change. We are now dying predominantly of chronic progressive disease as opposed to a century ago when we were dying of acute infections, obstetric and neonatal deaths and through trauma and malnutrition. This has huge implications for health service delivery over the next half century. Longevity and the inter-generational age also means that for the current generation, exposure to dying and death is far less than any other time in history.

The majority of us will have warning of our death whether from cancer, end-stage organ failure or progressive neurodegenerative diseases. For many people, there will be period after disease modifying treatments have stopped working.

Prevalence of palliative care needs in the acute care sector

Within the public hospital system a recent Australian audit noted that one in three inpatients (excluding intensive care unit, psychiatry, paediatrics and obstetrics) had a palliative intent as the goal of care. [6] **This means that it is impossible that every person can or should be seen by specialised palliative care services.** The onus is on palliative care services to find ways to help referrers identify the people with the most complex needs and offer the additional expertise and support that specialist services can offer.

Who is seen and who is not seen

Most services are able to describe in detail the people with life-limiting illnesses who are referred to them, but have little or no idea about the people who are *not* referred to them. In Australia, this means that services cannot describe the one in two people who will never be referred to them.

The team at Flinders University is one of a handful of research teams in the world who are specifically seeking to research what is happening to the people with life-limiting illness who are not referred to a specialist palliative care service. [7] Using a whole-of-population approach means that people who are not seen can be part of planning for future services, especially if unmet needs are identified. In South Australia, there is no apparent discrepancy between access to services between residents of metropolitan and rural locations. For people from culturally and linguistically diverse backgrounds, although uptake rates of specialist services may be lower, the accuracy of referral is highest in this population. Accuracy here refers to both true positives (former caregivers who perceived they needed the service and received it) and true negatives (former caregivers who perceived they did not need the service and did not access it). People from culturally and linguistically diverse backgrounds had significantly higher rates of family support than the rest of the population. The number of respondents from Aboriginal or Torres Strait Islander communities was too small to draw any conclusions.

Access to services – diagnosis of cancer when compared with other diagnoses

Systematically, people with diagnoses other than cancer are missing out on access to specialised palliative care services. [8] For more than a decade it has been acknowledged that the needs for people in such circumstances are very similar to people with cancer. Yet, consistently across the country, people with end stage organ failure including heart failure, respiratory failure (mostly emphysema), hepatic failure, renal failure and neuro-degenerative diseases systematically miss out on services.

This again has been quantified by taking a whole-of population approach in South Australia and it is clear that there is a significant and sustained gap across the community in this regard. Population estimates are that for every two people seen with cancer, a person with

a non-cancer diagnosis should be seen by specialist palliative care services. This is not the case, and specific processes need to be put in place to improve this access. The reasons for systematically poor access include limitations on both by referrers and also by specialist palliative care services. [9,10,11]

Accuracy of referral

Having said this, Omnibus data suggest that the accuracy of referral (those who perceive they need services and receive them and those who perceive they did not need services and did not use them) is quite good across South Australia from recent whole-of-population data. [12] It is likely that this reflects the rest of the country reasonably.

Accessing services

Access to specialist palliative care services is likely to be achieved by people who are well versed in navigating the health system. There is a need for an active process for seeking the people with the most complex needs, not those who can find their way through the system. This should not be a pre-requisite to accessing specialist services, and **the responsibility lies with specialist palliative care services to ensure that the people with the most complex needs are the ones who take absolute priority.**

Access to specialised palliative care services by geographic region

Services tend to be geographically located in more established communities. Services are not well distributed particularly in the peri-urban areas of large cities. In geocoding services nationally, there are manifest problems in the availability of services particularly in the community.

Access to specialised palliative care services – services responsibilities

Services have to take a responsibility to move beyond passive case finding. There is an urgent need to take responsibility for the whole of the population within a geographic area for each service. This means that any fragmentation between inpatient services, consultative services, outpatient services and community services has to be engineered out of the system. Whole of geographic region processes mean that on a needs basis, such services should provide care in the community linked with inpatient services in both the public and private sector.

Do specialist palliative care services make a difference? [13]

It is critical to rigorously document the beneficial outcomes resulting from actively incorporating palliative care into the health system. Without these data, one could reasonably ask why there should be an investment of public money in specialist palliative care.

For the individual patient, studies have demonstrated:

- improved symptom control;

- higher levels of satisfaction with services;
- better comfort in the last two weeks of life;
- improved quality of dying; and
- better meeting the needs of people at the end of life

if a specialist palliative care service is involved in care. [12,14-21]

For **caregivers**, there are significant associations between palliative care service involvement and:

- better met caregiver needs;
- greater satisfaction with the care provided;
- less anxiety while in the caregiver role; and having relinquished the role:
- **better spousal survival having relinquished the role;** and
- improved ability to move on with one's life. [2,22,23,24]

At a **health service level without compromise to survival**, the data support:

- reduced number of inpatient bed days
- reduced number of hospital admissions; and
- reduced costs with the use of specialist palliative care. [20,25,26,27]

Primary Care

The interface with primary care is crucial for good palliative care to be delivered across the nation. Some services have systematically disenfranchised primary care, and this will come at a cost to patients (in terms of continuity) and sustainability of services (many general practitioners provide unparalleled care for people with life-limiting illnesses).

A Commonwealth funded study has highlighted the pivotal nature of good primary care at the end of life. [25] The Palliative Care Trial (PCT) explored the use of a single Medicare-funded case conference at the time a person was referred to specialist palliative care services. This was compared to usual specialist palliative care. The group who had a case conference had **25% fewer admissions to hospital**. Such engagement needs to be part of every specialist palliative care service's model of care.

Specialist services

Key roles for specialised palliative care services

One could argue that the primary role of specialised palliative care services is to provide **clinical care** for people with the most complex needs and support colleagues in their care of people wherever they are in the health system. A key partnering role is that of furthering the evidence base to improve the quality of care that is offered. That **research** agenda has to come before there can be wider education. Given that approximately one in two people who are palliative will never see a specialist palliative care service, the research has to inform the clinical care provided by a large number of practitioners across the community in order to improve the quality of care that is offered universally to people who will never be referred to specialised palliative care services. **Education** and support for colleagues – nursing, medical and allied health – becomes a key role in care as the evidence base is

expanded. The process of continuing education is crucial if the best possible care is to be provided in an area with a rapidly expanding evidence base.

All three components (clinical care, research, education) should have time and resources set aside by each specialist service, *even within the current funding platforms*. Given that specialist palliative care services are, and always will be, referral-based services, specialist services that are only providing clinical care are not fulfilling the role in a way that builds capacity systematically for the future.

Service Provision

In terms of service provision, services have largely grown up organically. Very few services have been designed from the ground up to meet the needs of the population that they serve. The transition from growth (where very few people wanted to be referred to palliative care) to a place where there is demand that outstrips service provision means that there is a generational change in how services need to consider the work that they do and the models of service delivery that are employed. There are wide variations in models and funding and, at times, real barriers put in place by palliative care services to limit the service that is offered or the referrals that can otherwise be made.

National initiatives

Palliative Care Australia's systems approach to needs-based care

The national body has an approach over the last decade which says that there are a number of people whose needs are already being met, a number of people whose needs will best be met by time-limited involvement to deal with a particular problem and a very small group of people who will need consistent long-term input from a specialised palliative care service from the time of referral until death.

National initiatives – availability of medications

The ministerially appointed Cancer Strategies Group in the late 1990's identified the need for improved availability of key medications for palliative care patients in the community. A whole-of-government process explicitly included the Therapeutic Goods Administration, Pharmaceutical Benefits Advisory Committee, Cancer Council Australia, Cancer Australia, the Australian New Zealand Society of Palliative Medicine, Palliative Care Australia, General Practice Advisory Committee, the Australian Pharmaceutical Advisory Committee, the National Prescribing Service and the Pharmaceutical Benefits Branch. This generated Australia's first patient-defined section of the Pharmaceutical Benefits Scheme which was for palliative care patients and initiated in February 2004. [28] Through a national survey of clinicians working in palliative care the twenty five top symptoms were surveyed in order to understand where key medications were not available on the Pharmaceutical Benefits Scheme. A list of medications were drawn up which included a number of medications for which there was not sufficient evidence to generate a Therapeutic Goods Administration

application. The Commonwealth commissioned work to fill these very specific gaps in knowledge. This program has become the Palliative Care Clinical Studies Collaborative (PaCCSC). This is the world's largest clinical studies collaborative in palliative care and, has to date, randomised more than seven hundred and fifty participants to eight phase III clinical trials across twelve sites in order to answer very practical questions about day-to-day clinical practice. This has been complemented with phase IV work in current patterns of care across the symptoms that are being studied. These symptoms include delirium (as noted earlier), complex pain, dyspnea, nausea, constipation and anorexia. The first of these studies has been submitted to a peer reviewed journal for critique. This has also led to the development of "rapid pharmacovigilance" program that has already engaged clinicians internationally using the research data management system of CareSearch to consecutively enrol patients with frequently used medications in palliative care looking specifically at benefit and toxicity at set time points using internationally standardised measures. This is a model that can be used to inform public policy in all areas of prescribing by systematically describing the net clinical effect in day-to-day clinical use.

Systems performance and benchmarking of palliative care in Australia

Palliative care in Australia also leads the world in point of care data collection for quality of care. [29] With the exception of the emergency departments, intensive care units and some surgical sub specialities, the level of clinical accountability in palliative care in the community and inpatient units is second to none in Australia. The Palliative Care Outcomes Collaborative (PCOC) allows true benchmarking. This is world-leading with no other country in the world having this level of clinical accountability. This has led to demonstrable improvements in clinical care across the system including patient care and caregiver supports. This federally funded program has been running since 2006 and now collects quality of care data at point-of-contact on more than 80% of all people referred to specialist services in the country. This is crucial for the improvement of quality of care that needs to be offered.

Commonwealth funded needs-based tool

The Commonwealth has funded the development of an Australian needs-based tool. [30,31] This has two major audiences:

- General Practitioners and other referrers in order to establish whether this person at the end of life has unmet needs and, if so, by whom these needs should best be met. This most likely is referral for other aspects of care within the network of that particular clinician but may lead to referral to a specialist palliative care service. It also allows complex needs to be outlined quickly and efficiently in making a referral.
- For specialist palliative care services having done a thorough multi-disciplinary assessment of this particular patient, are the needs of this person in the context of their family and support network going to be better met by access to specialist palliative care or are those needs already being met? For people whose care is

shared with specialist palliative care services and their general practitioner, it also allows review as time goes by.

Undergraduate education in palliative care

Australia has invested in developing curricula and resources to support these curricula in palliative care in a nationally coordinated way. [32] Although this still depends directly on uptake at the level of each university faculty or school (or even each course), the resources are high quality. The resources create an expectation that a palliative approach is an integral part of training clinicians across the spectrum of disciplines represented in health sciences.

Post-graduate education in palliative care

Educationally, Australia is well placed with post graduate programs at a graduate certificate, graduate diploma, masters, Master of Science and doctoral levels. The investment by the Commonwealth in bursaries in masters and doctoral students has created a number of palliative care academics who continue to contribute at an international level. It is a well educated workforce with a large number of people holding postgraduate specialist qualifications in palliative care in both nursing and medicine, and increasingly in allied health.

Vocationally, although a relatively recent sub-specialty, Australia has consistently led the world in the care of people at the end of life. For example, it was the first country to have a specialist training scheme, established in 1988 through the Royal Australasian College of Physicians. This placed us in a position that has ensured that the care of people at the end of life has continued to improve over the last two and a half decades. This built on a century of providing hospice care in a small number of units across the country.

Informatics and evidence-based resources

CareSearch is world-leading in providing current evidence for clinical practice and service delivery in palliative care. [33] This innovative program interrogates the United States' National Libraries of Medicine in real time using more than fifty verified searches that have been painstakingly researched. Together with this, CareSearch has brought together communities of practice in palliative care nursing, palliative care allied health and other interest groups. It provides information directly to patients, their families as well as to general practitioners and specialist services. It includes more than eighty government reports from the last two decades as well as more than 2200 abstracts exploring the provision of palliative care since 1980 from Australia. Many of these abstracts have not been converted into peer review publications and so this is an important source of key information about care.

International comparisons

Service delivery

By international standards, the care that is offered in Australia is excellent. The Economist review of palliative care globally in 2010 ranked Australia equal first in the integration of services with other health care providers and with the care that was actually provided. It also reflects that many other countries around the world have very poor infrastructure for palliative care. For example the presence of palliative care within the United States is far less systematically distributed than it is in Australia.

Academic palliative care in Australia and internationally

Palliative care academically in Australia is world leading. We continue to have research programs that are answering practical questions about how to improve the quality of care and the ways of delivering that care. In publications, Australia ranks incredibly highly [34] and *per capita*, is leading the world in palliative care research.

Research in palliative care

The research that is being done includes research that can inform other areas of health care. For example, the Palliative Care Clinical Studies Collaborative (PaCCSC) is conducting the world's largest trial of the pharmacological management of delirium. Delirium currently costs the health system billions of dollars a year around the world and yet this study will establish whether anti-psychotic medications have any benefit in that setting.

Current challenges

Population health planning principles

Death rates, causes of death and unmet needs are all well described, and yet population-based planning principles are poorly used in planning or reviewing specialist palliative care services, service structures or resourcing. For example, if there is sufficient workload to justify another medical oncologist, then there will be a direct proportional increase in the work for the palliative care team. This should not require separate funding proposals, but should be built into the business case by the referring service, be it in oncology or any other specialty that should be referring to palliative care.

For specialist palliative care services, the responsibility to triage by complexity of needs is paramount. With this in place, there is the opportunity to ensure a more transparent and equitable distribution of access to services.

Isolated practitioners

States and territories all have some sort of service level role delineation / service capability framework across the spectrum of clinical care including palliative care. For larger services this works well. For smaller services, the concept is that there will be formal networks with larger services to provide higher level care for people with more complex needs. These networks vary across Australia from strong formal ties to places where there is no support

for some services that comprise a fractional appointment of a nurse who has been thrust into the role. Every clinician should be able to identify a network of every discipline required in the comprehensive care for someone at the end of life, regardless of the administrative boundaries, even in the smallest service. These networks are crucial to help to further improve the quality of care, and should not rely on informal person-to-person contacts.

Varying models of service delivery and widely varying criteria for service involvement

There needs to be a rapid move towards standard criteria for referral to specialist palliative care services nationally with standard criteria also, where appropriate, when a person's care no longer needs to involve the specialist team. This will help referrers understand when to initiate referral and also help specialist services manage workload with more equity for the whole population that they serve.

With similar levels of resourcing, there are widely varying models of care and access to services. Such anomalies need to be explored in order to minimise such needless variation and optimise outcomes for people at the end of life.

For example, every tertiary hospital should have, as a basis for ongoing accreditation, a functioning acute symptom control / assessment unit with around-the-clock senior clinicians on call to accept care (including accepting referrals directly from Emergency Departments in the same way that any other clinical sub-specialty does). [35] Such a model should also include outpatient or rooms-based care. Without this, there is the assumption that specialist palliative care is only for people so sick that they need to be in hospital or so unwell they cannot leave their house.

Varying levels of staff capability – opportunities for training

In palliative medicine specifically, there are opportunities being missed to improve the evidence base for clinical care and service delivery models. In internal medicine, every other sub-specialty allows one of three years of a trainee specialist's advanced training to be committed to doctoral studies. Unfortunately, this is not the case in palliative medicine, and the sub-specialty is poorer for this.

Varying funding models and the need for more resources

Uniform funding models to ensure equity of access to specialist palliative care services across the whole community are needed. Simply injecting more resources will not solve the problems unless models of service delivery are also refined at the same time. As funding is made available, there must be an absolute commitment to training positions including nurse practitioners and medical registrars. Most major cities have unfilled senior medical posts, so it is not simply a matter of providing more money, without ensuring the next generation of the workforce is supported in training and that the models of service delivery are optimised.

Varying access to services

As highlighted, people with a diagnosis other than cancer are systematically missing out on access to specialist palliative care services. [12] Specialist palliative care services need to take responsibility to redress this inequity.

Recommendations

1. Access through needs-based care

Ultimately, there is an urgent need to adopt universally a needs-based approach that is nationally consistent to ensure the people with the most complex needs are systematically identified in primary and tertiary care and offered the opportunity for a comprehensive assessment by a specialist palliative care service. This includes the need for nursing, social work/psychosocial assessment as well as medical assessment. This is especially the case for people whose life-limiting illness is not cancer. [30,31]

Such a process requires population-based planning from data that are readily available.

An ability to improve clinical outcomes- universal benchmarking

There are wide variations in the core outcomes such as symptom control across Australia. Such variations are *not* simply due to variations in resources available. Every specialist palliative care service should be actively engaged in service improvement by participating in the Commonwealth-funded Palliative Care Outcomes Collaborative (PCOC) and should be setting explicit goals to improve the care that is delivered.

Nationally consistent referral thresholds / admission and discharge criteria from specialist services

Wide variations also exist regarding who is seen or not seen by specialist palliative care services. This is confusing to referrers and does not foster equity of access. Nationally consistent approaches are needed for service admission and discharge criteria.

Genuine and sustained engagement with primary care by specialist services

Primary care is the backbone of the non-hospital sector (and much of the non-metropolitan hospital sector) and specialist palliative care services need to actively engage with primary care. Without doing so, quality of care is compromised and continuity of care is lost. Engagement through Medical Benefits Schedule case conferencing should be a standard of care for every person referred to specialist services. [25,36]

New and emerging roles

Training positions in nursing, medicine and allied health must be a priority for any new funding. Substantive positions in allied health with speciality skills in palliative care are urgently needed in occupational therapy, physiotherapy, social work and pharmacy. Nurse practitioner training positions need to be rapidly expanded.

Caregivers

There needs to be far greater emphasis in supporting caregivers during the role and having completed the role. This includes long term studies to evaluate the impact of caring in this setting and minimising long term health consequences. A key measure of success of good palliative care should be the health and wellbeing of caregivers in the years after having completed their caring.

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ORIGINAL CONTRIBUTION

Factors Considered Important at the End of Life by Patients, Family, Physicians, and Other Care Providers

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DYING PATIENTS CONFRONT complex and unique challenges that threaten their physical, emotional, and spiritual integrity. The Study to Understand Prognosis and Preferences for Outcomes and Risks of Treatments (SUPPORT) documented that many patients die prolonged and painful deaths, receiving unwanted, expensive, and invasive care.¹ Patients' emotional suffering at the end of life can be profound, yet physicians are too frequently ill equipped to address this suffering.^{2,3} In response, medical societies, health care organizations, and the public have identified improved end-of-life care as a high national priority. The American Medical Association and the Institute of Medicine have outlined goals for improved care of the dying, and The Robert Wood Johnson Foundation has devoted millions of dollars to public education on this issue through the Last Acts initiative.⁴⁻⁶

These efforts depend, in part, on certain presumptions regarding how dying patients and their families define quality at the end of life. During the latter part of the 20th century, advances in biomedical technology propelled us to see a "good" death as one involving

Context A clear understanding of what patients, families, and health care practitioners view as important at the end of life is integral to the success of improving care of dying patients. Empirical evidence defining such factors, however, is lacking.

Objective To determine the factors considered important at the end of life by patients, their families, physicians, and other care providers.

Design and Setting Cross-sectional, stratified random national survey conducted in March-August 1999.

Participants Seriously ill patients (n = 340), recently bereaved family (n = 332), physicians (n = 361), and other care providers (nurses, social workers, chaplains, and hospice volunteers; n = 429).

Main Outcome Measures Importance of 44 attributes of quality at the end of life (5-point scale) and rankings of 9 major attributes, compared in the 4 groups.

Results Twenty-six items consistently were rated as being important (>70% responding that item is important) across all 4 groups, including pain and symptom management, preparation for death, achieving a sense of completion, decisions about treatment preferences, and being treated as a "whole person." Eight items received strong importance ratings from patients but less from physicians ($P < .001$), including being mentally aware, having funeral arrangements planned; not being a burden, helping others, and coming to peace with God. Ten items had broad variation within as well as among the 4 groups, including decisions about life-sustaining treatments, dying at home, and talking about the meaning of death. Participants ranked freedom from pain most important and dying at home least important among 9 major attributes.

Conclusions Although pain and symptom management, communication with one's physician, preparation for death, and the opportunity to achieve a sense of completion are important to most, other factors important to quality at the end of life differ by role and by individual. Efforts to evaluate and improve patients' and families' experiences at the end of life must account for diverse perceptions of quality.

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the fight against disease. Partly in response to this view, the modern hospice movement emerged, redefining a good death as one that included acceptance and closure, most often at home. Unfortunately, empirical support for a notion of a good death that might best structure end-of-life care is lacking, as is a comprehensive understanding about how the definition of a good death might vary across relevant constituencies.

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Caregiving for the terminally ill: at what cost?

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This literature review exposes the nature and extent of physical and psychosocial morbidity and economic disadvantage, home palliative caregivers suffer as a direct result of their caregiving role. Research has demonstrated that caregivers providing support to individuals receiving palliative care report unmet needs for information, communication, service provision and support from health and community services. Three sets of challenges are highlighted in this literature review which help explain why the needs of home palliative caregivers are largely unmet: (i) barriers to seeking help; (ii) a dearth of research-based interventions focused on reducing the negative aspects of caregiving; and (iii) a number of impediments to effective policy and service development for family caregivers. Furthermore, invited submissions from caregivers echoed and confirmed the issues reported in the literature. Recommendations for enhancing caregiver support are outlined. *Palliative Medicine* 2005; **19**: 551–555

Key words: informal care giving; unmet needs; impact of caregiving; service provision; barriers; palliative care research

Introduction and objectives

Many individuals are finding themselves becoming the primary care providers for ill and disabled family members. Primary caregivers are defined as people who regularly provide the most assistance with one or more of the core activities of communication, mobility, transport, housework and self-care.¹ We live longer, but with compromising medical conditions and increased costs of health care. Consequently, families are increasingly replacing skilled health workers in the delivery of unfamiliar complex care. The caregiver role has changed dramatically from promoting convalescence to providing high technology care and psychological support in the home.²

Palliative care is the specialized health care of dying people, which aims to maximize quality of life and assist family and caregivers during and after the death of a loved one.³ Although approximately one-third of all patients receiving palliative care services die at home, studies in Australia and the UK reported that up to 90% of terminally ill patients spend the majority of their last year of life at home.^{4,5} Thus, home palliative care would be impossible for many people without the support of caregivers.⁶

The demand for palliative care services within the home has increased due to the reduced availability of hospital beds, a desire for less institutionalized care and an aging population where the morbidity and mortality associated with illnesses such as cardiovascular disease, cancer and respiratory disease increase with age.⁷ Some 50–70% of terminally ill patients may prefer to die at home in the comfort of familiar surroundings.⁸ The preference for a home death is compatible with government's objective to shift health care away from public institutions and into the community, particularly when there is compelling evidence to indicate that public spending on care is reduced when care is shifted to the community.⁹ Yet there is considerable evidence in the literature that the burden of caregiving is adversely affecting family caregivers who lack adequate resources or who are insufficiently prepared for this new complex role.^{2,10–12}

This literature review was undertaken as a background:

- to inform an Australian National Inquiry into the plight of carers of the latest national and international challenges and unmet needs and
- to consequently help influence policy and practice related to support caregivers.

Thus, this literature review describes the nature and extent of the impact of caregiving on the physical, psychosocial and economic aspects of life of palliative caregivers, highlights their needs and identifies existing challenges in enhancing the knowledge, skills and

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Original Article

Palliative Caregivers Who Would Not Take on the Caring Role Again

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Abstract

Context. Health and social services rely heavily on family and friends for caregiving at the end of life.

Objectives. This study sought to determine the prevalence and factors associated with an unwillingness to take on the caregiving role again by interviewing former caregivers of palliative care patients.

Methods. The setting for this study was South Australia, with a population of 1.6 million people (7% of the Australian population) and used the South Australian Health Omnibus, an annual, face-to-face, cross-sectional, whole-of-population, multistage, systematic area sampling survey, which seeks a minimum of 3000 respondents each year statewide. One interview was conducted per household with the person over the age of 15 who most recently had a birthday. Using two years of data ($n = 8377$; 65.4% participation rate), comparisons between those who definitely would care again and those who would not was undertaken.

Results. One in 10 people across the community provided hands-on care for someone close to them dying an expected death in the five years before being interviewed. One in 13 (7.4%) former caregivers indicated that they would not provide such care again irrespective of time since the person's death and despite no reported differences identified in unmet needs between those who would and would not care again. A further one in six (16.5%) would only "probably care again." The regression model identified that increasing age lessens the willingness to care again (odds ratio [OR] 3.94; 95% confidence interval [CI] 1.56, 9.95) and so does lower levels of education (OR 0.413; 95% CI 0.18, 0.96) controlling for spousal relationship.

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Preference for place of care and place of death in palliative care: are these different questions?

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Place of death is at times suggested as an outcome for palliative care services. This study aimed to describe longitudinal preferences for place of care and place of death over time for patients and their caregivers. Longitudinal paired data of patient/caregiver dyads from a prospective unblinded cluster randomised control trial were used. Patients and caregivers were separately asked by the palliative care nurse their preference at that time for place of care and place of death. Longitudinal changes over time for both questions were mapped; patterns of agreement (patient and caregiver; and preference for place of death when last asked and actual place of death) were analysed with kappa statistics. Seventy-one patient/caregiver dyads were analysed. In longitudinal preferences, preferences for both the place of care (asked a mean of >6 times) and place of death (asked a mean of >4 times) changed for patients (28% and 30% respectively) and caregivers (31% and 30%, respectively). In agreement between patients and caregivers, agreement between preference of place of care and preferred place of death when asked contemporaneously for patients and caregivers was low [56% (κ 0.33) and 36% (κ 0.35) respectively]. In preference versus actual place of death, preferences were met for 37.5% of participants for home death; 62.5% for hospital; 76.9% for hospice and 63.6% for aged care facility. This study suggests that there are two conversations: preference for current place of care and preference for care at the time of death. Place of care is not a euphemism for place of death; and further research is needed to delineate these. Patient and caregiver preferences may not change simultaneously. Implications of any mismatch between actual events and preferences need to be explored. *Palliative Medicine* (2008); 22: 787–795

Key words: caregivers; health service planning; palliative care utilisation; place of care; place of death

Introduction

Palliative care has developed from a philosophical critique of the professionalisation and institutionalisation of death.¹ As a consequence of this orientation, much of the development of palliative care services has been focused

on the goal of increasing the rate of home deaths, on the presumption that home death is the ideal.²

Data from patients with cancer have already challenged such an assumption in terms of its absolute importance. The place of death may not always be a dominant concern of the dying person.³ When looking at mean rank order of important factors at the time of death, the first ranked by patients, bereaved family members and physicians was freedom from pain, with death at home rated tenth.³

Palliative care providers, dying patients and their caregivers are all engaged in complex calculations to assess patients' and caregivers' wishes, the options available, the impact of the burden of caring, the ability to effectively manage difficult symptoms in the home setting and to maintain the dying person's comfort and dignity,

Ethics approval: This trial was approved by all 12 relevant independent HRECs and IRBs including the Australian Department of Veteran Affairs and Health Insurance Commission, Canberra, Australia. The trial is registered with the ISRCTN81117481 (<http://www.controlled-trials.com/isrctn/trials/81117481/0/81117481.html>).

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Can assessing caregiver needs and activating community networks improve caregiver-defined outcomes? A single-blind, quasi-experimental pilot study: Community facilitator pilot

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Abstract

Background: Although the unit of care in palliative care is defined as the patient and their family, there are few rigorous studies on how to improve support for family and friends as they take on the role of caregiver for someone at the end of life.

Aim: Separate to patient evaluation and care, this pilot study aimed to define the feasibility and possible outcome measures to evaluate routine assessments and supports specifically for caregivers.

Design: In a quasi-experimental design, two communities were included: one received standard specialist palliative care support and one additionally was allocated to a community network facilitator who assessed caregivers' needs and helped mobilize the caregiver's own support network or initiated contact with other community supports in three planned visits. Data were collected at baseline, 4 and 8 weeks using three caregiver assessment tools. Within group comparisons were made using Wilcoxon signed rank test and between group using the Mann-Whitney U-test.

Participants: Sixty-six caregivers participated.

Results: At 8 weeks, participants in the intervention arm showed significant within-group improvement in caregiver fatigue, sufficient support from others, decreased resentment in the role, greater confidence in asking for assistance and were better able to find resources and support. No between-group changes were seen in this pilot study.

Conclusions: There were objective measures of improved support within the intervention group over time for caregivers through the active engagement of the community network facilitator. This pilot supports the case for an adequately powered study.

Keywords

Community care, family caregivers, palliative care, quasi-experimental design, social capital, social networks

Introduction

There is an expectation within the community that when a family member or friend gets sick, care will be provided at home by the family.¹ In this pilot study 'caregiver' is defined as a family member, parent, partner, significant other, friend or neighbour who provides substantial home-based care on an unpaid basis to someone with a life-limiting illness.² Health and social services rely on such caregivers as the backbone of community end-of-life care

across the world,^{3,4} yet many caregivers report substantial unmet needs.^{5,6} Such care can come at a tremendous price while in the role, and subsequently, with poor health and an associated increase in mortality in spousal caregivers who do not access help.⁷⁻¹⁰ Although many people find such roles to be an opportunity for growth, some struggle with the role while others resent the role or would not take it on again.^{1,3,11}

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Brief Communication

A point prevalence survey of hospital inpatients to define the proportion with palliation as the primary goal of care and the need for specialist palliative care

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Key words

palliative care, burden of disease, health service planning, needs assessment.

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Abstract

The direct burden of people whose goal of care is a palliative approach has not been estimated in the acute care setting. Using a single time point, cross-sectional survey of all inpatient beds, an estimate was generated across a network of three South Australian public hospitals. One in three inpatients had a palliative approach as the goal of care and of these, only one in five had been referred to specialist palliative care services. Those referred were significantly more likely to have cancer and be younger men. Active recognition and documentation that a palliative approach frames the goals of care for this person needs to be incorporated more systematically into clinical practice in the acute care setting. At the same time, triggers for needs-based referral for specialist assessment should be implemented. Specialist palliative care services must also provide direct care for a wider range of patients than just those with cancer.

Cancer and chronic illnesses are more frequently becoming the cause of death in our ageing population.¹ There is pressure on the health system to provide increasingly complex and expensive treatments using a finite resource.² The costs of care at the end of life are high, with people in the last 6 months of life consuming 21% of healthcare costs and occupying 24% of hospital days.² Despite this investment, the need for good palliation is often unmet.³

Services must be designed better to meet the needs of people with chronic progressive illnesses and their caregivers. Documented benefits of the appropriate involvement of specialized palliative care services (SPCS) in the acute care setting include: improved symptom management;⁴ increased patient and carer support;^{5,6} reduced costs because of shorter length of inpatient stay; fewer unnecessary investigations and reduced intensive care utilization.^{7,8} No single measure captures the breadth of impact of SPCS involvement, so meta-analyses that focus

on specific aspects of care have only demonstrated marginal benefits.^{9,10}

The point prevalence of patients in the Australian inpatient public hospital population who would benefit from a palliative approach to care is not known. The aim of this survey was to quantify the proportion of people whose goal of therapy was palliative, and the percentage who had been referred to the SPCS.

South Australia (1.51 million people) has an older population than the country as a whole with 15.3% of people in 2008 aged over 65 years compared with 13.2% nationwide.¹¹ Southern Adelaide has a population of 350 000, with diverse socioeconomic and cultural backgrounds. This study includes all three public hospitals servicing southern Adelaide. The region is served by an SPCS that provides care in public and private hospitals, and through outpatient and community-based supports.

This was a cross-sectional (single day), contemporaneous case note point prevalence survey of each occupied inpatient bed in three acute hospitals by health professionals not directly involved in the care of the patients. Beds in the adult and neonatal intensive care units, emergency departments, paediatric, psychiatric, rehabilitation, obstetric and day procedure units were excluded.

Funding: This project did not rely on external funding.
Conflict of interest: None.

Specialist palliative care needs of whole populations: a feasibility study using a novel approach

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Background: Defining whether people with life-limiting illnesses (PLLI) who do not access specialized palliative care services (SPCS) have unmet needs is crucial in planning and evaluating palliative care. This study seeks to establish the viability of a whole-of-population method to help characterize SPCS access through proxy report. **Methods:** Questions were included in a piloted annual face-to-face health survey of 3027 randomly selected South Australians on the need for, uptake rate of, and satisfaction with SPCS in 2000. The survey was representative of the cross-section of South Australians by age, gender, socio-economic status and region. **Results:** One in three people surveyed (1069) indicated that someone 'close to them' had died of a terminal illness in the preceding five years. Of those who identified that a palliative service had not been used (38%, 403), reasons cited included family/friends provided the care (34%, 136) and the service was not wanted (21%, 86). Respondents with income >AU\$60 000 per year were more likely to report that a SPCS had been used ($P = 0.01$). People who had cancer as their life-limiting illness were more likely to access SPCS ($P < 0.001$). The results generate a model comparing SPCS utilization with client benefit. The survey was acceptable to interviewees. **Discussion:** Uptake rates of SPCS in this survey are consistent with other South Australian whole population estimates of SPCS utilization. Although there are limitations in this survey approach and the questions asked, this method can be developed to improve our understanding of the characteristics and needs of PLLI and their carers. *Palliative Medicine* 2004; 18: 239–247

Key words: epidemiology; health services needs and demands; needs assessments; palliative care utilization and trends; population studies

Introduction

Unlike many sectors of the healthcare system, there has been little population-based planning for the need for specialized palliative care services (SPCS*).³ Instead, SPCS have tended to develop in an ad hoc way, with

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A general palliative approach can be distinguished from the care of people with more complex problems where access to interdisciplinary palliative teams is likely to improve outcomes.^{1,2} We define SPCS as additional clinical services supplementing primary nursing and medical carers; SPCS generally include nursing and medical specialists or consultants in palliative care working in an interdisciplinary team. This acknowledges that the vast majority of palliative care is provided by primary carers with specialist consultative backup. Specifically identified funding and workforce planning for palliative care in Australia almost entirely relates to SPCS.

models of service delivery, funding sources, funding levels, disciplines involved, relationships with primary health care providers, and patient characteristics differing between services and health systems.^{1,4,5}

Initially, SPCS provided care for people with life-limiting illnesses (PLLI) who actively sought SPCS involvement. Services promoted the benefits of palliative care, leading to increasing referral rates earlier than the terminal phase of illness.^{4,6} Once referred, SPCS tended to see PLLI because they were referred, not because the defined needs of patients and their carers were better addressed as a result of service involvement.^{7,8}

As referrals to SPCS increase, clinical services are getting busier with healthcare resources not matching service growth. Should limited resources be available for:

- all people who seek SPCS
- SPCS seeking out PLLI with the most complex needs
- everyone facing a life-limiting illness

Populations who die without specialist palliative care: does lower uptake equate with unmet need?

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Background: In palliative care, the target population (all people with life-limiting illnesses and their family/caregivers) and the complexity of their needs from diagnosis to bereavement should define the subpopulation who access specialist palliative care services (SPCS). Have caregivers of patients who have not accessed SPCS had their needs met?

Methods: As part of a broader state-wide randomized face-to-face population health survey over six years (18 224 interviews, 71% response), questions were asked of people bereaved in the previous five years when someone close to them died an 'expected' death (39% of respondents). Questions included respondent demographics, the diagnosis of the deceased and, for one year, whether SPCS was of benefit (if used) or needed (if not used). Differential uptake rates were calculated for diagnosis, income, country of birth and age and 2 × 2 tables reflecting the accuracy of match of service with caregiver needs were generated for each group (accuracy = true positives + true negatives/total) × 100. **Results:** Uptake of SPCS was significantly lower in people with a non-cancer diagnosis (40% versus 62%; $P = 0.0001$), lower income (56% versus 61%; $P = 0.0006$) and people born where English was not the first language (52% versus 58%; $P = 0.0096$). The only subgroup where the accuracy of matching between palliative care service uptake and identified needs was lower than the overall average (83%) was where cancer was not the life-limiting illness (69%; cancer 86%). **Discussion:** SPCS under utilization has previously been described in the population subgroups explored in this study and assumed to equal unmet needs and poorer outcomes. Caregiver responses suggest that, except for people with a non-cancer diagnosis, lack of service uptake may not represent unmet needs. These results are limited to people with caregivers. *Palliative Medicine* 2008; 22: 43–50

Key words: access to health care; health services needs and demand; needs assessment; palliative care; health service research

Introduction

There are identifiable groups within the community who fail to access specialist palliative care services (SPCS) when they have a life-limiting illness. There is an assumption that these people are missing out on services and have unmet needs. In order to resolve whether they have unmet needs, researchers and service planners need to reach people who have and have not utilized services (including people who were offered a service but declined it).^{1,2} In palliative care, there are very limited data available on people who have not accessed

specialist services. Population-based planning recognizes that referral to a specialist service may not necessarily equate with need and, conversely, unmet or perceived needs may not always initiate a referral.³ In the Australian context, a distinction has been drawn in policy development between a palliative approach (a set of skills expected of every health professional who provides care for someone with a life-limiting illness) and specialized palliative care services (health professionals whose substantive training and work is in palliative care).⁴ This paper explores issues surrounding this second group of health professionals, and the specialized health service programmes within which they work.

A conceptual planning model for specialist palliative care has been developed, which distinguishes between those who need palliative care services and those who actually receive them. This helps to define two populations where need and service access may not match: those who received services

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Palliative care referral practices and perceptions: The divide between metropolitan and non-metropolitan general practitioners

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ABSTRACT

Objective: Late or non-referral of patients to specialist palliative care (SPC) services may affect patients' and their carers' quality of care. General practitioners (GPs) are key professionals in linking people with SPC. The aim of this article is to assess GPs' perceptions and SPC referrals for their patients with advanced cancer and differences between metropolitan (M GPs) and non-metropolitan GPs (NM GPs).

Method: Self-report survey mailed to a stratified random sample of 1,680 Australian GPs was used.

Results: Thirty-one percent (469) of eligible GPs returned surveys. More M GPs than NM GPs reported referring >60% of their patients for SPC ($p = 0.014$); and that a more comprehensive range of SPC services was available. The most frequently reported referral prompts were: presence of terminal illness (M GPs, 71%, NM GPs, 66%, *ns* (not significant)); future need for symptom control (69% *vs.* 59%, *ns*) and uncontrolled physical symptoms (63% *vs.* 54%, *ns*). Reasons for *not* referring were: doctor's ability to manage symptoms (62% *vs.* 68%, *ns*) and the absence of symptoms (29% *vs.* 18%, $p = 0.025$). Higher referral was associated with: having a palliative care physician or consultative service available; agreeing that all patients with advanced cancer should be referred, and agreeing that with SPC, the needs of the family are better met.

Significance of results: Referrals for SPC were primarily disease-related rather than for psychological and emotional concerns. Measures are needed to encourage referrals based upon psychosocial needs as well as for physical concerns, and to support GPs caring for people with advanced cancer in areas with fewer comprehensive SPC services.

KEYWORDS: Palliative care, Referral, Attitudes, Access, General practitioner

INTRODUCTION

Palliative care is "an approach that improves the quality of life of patients and their families facing the problems associated with a life-limiting illness" (World Health Organization, 2002). In Australia, general practitioners (GPs) and the primary healthcare

team are central to the ongoing provision of care at the end of life. Many people with advanced cancer are cared for until their death by their GP, with support from specialist health providers (Mitchell, 2002). Not all people with advanced cancer will require the intermittent or ongoing involvement of specialist palliative care (SPC) services (Currow & Nightingale, 2003) however, it is suggested that up to 90% will need referral to a SPC service for a more detailed assessment, with 70% requiring some ongoing contact and 30% requiring direct care in conjunction with their GP (Palliative Care Australia,

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Australian General Practitioners' and Oncology Specialists' Perceptions of Barriers and Facilitators of Access to Specialist Palliative Care Services

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Abstract

Purpose: Doctors in Australia play an important role in facilitating access to specialist palliative care (SPC) services for people with advanced cancer. This study aimed to describe doctors' perceptions of barriers to referring patients for SPC, and to identify triggers and facilitators for referral.

Method: Forty semistructured telephone interviews were conducted with doctors involved in the care of people with advanced cancer from a variety of settings.

Results: Six themes were identified: disease and treatment; psychosocial; communication and interpersonal issues; health services issues; timing; and, health professionals' skills. All doctors considered the presence and complexity of physical symptoms, stage of the disease and treatment orientation as important in decisions to refer for SPC. Less important were the psychosocial well-being and cultural characteristics of the person with cancer and their family. Factors reportedly affecting referral and access included health professionals' ability to communicate openly and honestly about disease progression, availability and location of SPC resources and doctors' expertise. Divergent views were expressed about appropriate timing for access. The predominant view that SPC is for management of physical symptoms may result in nonreferral of those who have complex problems without physical symptoms.

Conclusions: Given the complex relationship between psychological and physical well-being and health-related quality of life, it is important that all factors contributing to patient well-being are identified. Routine use of objective measures of unmet and complex needs may help identify people who are likely to most benefit from SPC and optimize access, regardless of timing, stage of disease, and treatment orientation.

Introduction

TRADITIONALLY, specialized palliative care (SPC) has been viewed as terminal care, accessed when all disease-controlling options are exhausted.¹ In contrast, palliative care (PC) is now advocated within an integrated, multidisciplinary care framework, in which all forms of treatment are considered (including palliative care) throughout the disease trajectory. PC is also proposed to be needs focused, and aimed at meeting the physical, psychological, social and spiritual problems of the patient and their family.^{1,2}

Intervention by SPC services results in improved outcomes for many patients and families.^{3,4} The needs of people with

advanced cancer and their caregivers are complex,⁵⁻⁷ however, the majority of referrals for SPC are for the management of physical symptoms in the terminal phase of a life-limiting illness.^{8,9} While SPC services are widely available, people with cancer and their caregivers often report a range of unmet needs, including psychological, physical, information, and communication needs.¹⁰

Although not all people with advanced cancer require SPC,^{11,12} it is important that patients and caregivers with unmet needs are identified and offered appropriate care. Approximately 90% of SPC referrals in Australia are cancer-related,¹³ although there is a lower proportion of such referrals in other countries.¹⁴ Given the high rate of cancer-related

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Australian palliative care providers' perceptions and experiences of the barriers and facilitators to palliative care provision

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Abstract

Objective People with advanced cancer who may benefit from specialised palliative care (SPC) do not necessarily access such services.

Methods To obtain a deeper understanding of issues affecting access to SPC, five focus groups were undertaken with nurses (35), physicians (three), allied health professionals (seven) and an academic involved in providing care.

Results Thematic analysis revealed that palliative care providers consistently view palliative care as a broad holistic approach to care benchmarked on good symptom management. Whilst participants themselves perceived SPC as aiming to maximise the quality of life of the patient and family across all domains of care, they perceived that some health professionals and community members viewed

palliative care largely as symptom control and terminal care for access after all disease-modifying treatment has been exhausted. Concern was expressed that such misconceptions were an important barrier to timely SPC. Participants did not nominate a time or particular milestone in the disease process which should prompt referral and suggested that SPC be available at any time where needs are complex and/or are not being met.

Conclusion Failure to properly recognise and understand the breadth of care provided within the palliative care framework may result in people with advanced cancer and their caregivers not accessing SPC services or accessing them too late to receive maximum benefit. Education may be required to promote the holistic nature of SPC services amongst health professionals and the community and to help realise the potential benefits to patients, families and health professionals resulting from timely access to SPC services.

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Keywords Palliative care · Neoplasms · Health services
accessibility · Referral and consultation

Introduction

Recent years have seen a shift in the delivery of specialised palliative care (SPC) from a focus on terminal care provided when all disease controlling options were exhausted [1] to its provision as needed throughout the disease trajectory to meet the physical, psychological, social and spiritual problems of the patient and their family, within an integrated, multi-disciplinary care framework where all possible forms of treatments are considered [1–3].

People with advanced cancer and their caregivers have multi-dimensional and complex needs [4–6]; and interven-

ORIGINAL ARTICLE

Comfort in the last 2 weeks of life: relationship to accessing palliative care services

David C. Currow · Alicia M. Ward · John L. Plummer ·
Eduardo Bruera · Amy P. Abernethy

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Abstract

Introduction Specialised palliative care services (SPCS) aim to address the needs of patients and caregivers confronting life-limiting illnesses but only half of the potential cohort are referred. Randomised controlled trials of SPCS provision can no longer be ethically justified so there is a need to develop new methods to evaluate the net impact of SPCS for the whole community, not just for those who access SPCS. The aim of this study was to assess whether perceived comfort in the last 2 weeks of life was associated with accessing SPCS. **Methods** This study utilised a whole-of-population random survey ($n=4,366$) in South Australia. A total of 802 respondents had someone close to them die within the last 5 years due to a terminal illness, and they had the complete

data. A subsequent question was asked whether SPCS had been accessed. Perceived comfort levels for those who had used SPCS were compared with those who did not by using stereotype logistic regression, weighted to a standardised population.

Results Higher levels of comfort of the deceased having been assessed 'very comfortable' was associated with the use of SPCS ($p=0.04$; odds ratio, 1.78; 95% confidence interval, 1.02–3.08). For people who accessed SPCS, 13.3% were reported as 'very comfortable' compared with 8.0% without SPCS. Almost one half of respondents (48.4%) reported that the deceased was considered 'uncomfortable' or 'very uncomfortable', irrespective of SPCS access.

Discussion While this study provides further incremental evidence of benefit from access to SPCS, there is much that still needs to be done to improve care for the whole community at the end of life.

Keywords Palliative care service access · Population planning · Proxy reporting · Quality of care · End-of-life care/terminal care/hospice care

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Introduction

Patients and their family members identify comfort and good symptom control as essential components of good end-of-life care [21, 36, 47, 51, 53, 54]. Specialised palliative care services (SPCS) have developed to support a range of health professionals to address better the needs of patients and families confronting life-limiting illnesses. There is a need to understand all aspects of the benefits derived from SPCS access.

For patients, involvement of SPCS improve the "quality of dying" [55], pain assessment and management of people dying in nursing homes [43, 44] and symptomatic manage-

International Perspective: Outcomes of Palliative Oncology

David C. Currow,^a Jane L. Wheeler,^b and Amy P. Abernethy^{a,b}

Accompanying the ascendance of cancer as a leading cause of death worldwide is a new set of global health priorities focused on palliative care—the relief of symptoms and suffering, optimization of functional status, and quality of life for those with advanced, potentially life-limiting illnesses. In high-income countries, palliative care improves outcomes for patients, caregivers, provider organizations, and health systems. Data are not yet available to demonstrate similar benefits in low- and middle-income countries, where access to even the most basic palliative interventions (eg, opioids for pain management) is inadequate and unevenly distributed. This article describes current global disparities in the availability of palliative care. We make the case for international prioritization of palliative care as a critical strategy for improving outcomes for people with cancer and their caregivers worldwide.

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This year, globally, more than 8 million people will die as a direct result of cancer, many of whom will have had their lives substantially shortened, eclipsing the annual mortality of AIDS, malaria, and tuberculosis combined. By 2030, the annual death toll from cancer is expected to rise to 17 million, and 75 million people are projected to be living with a cancer diagnosis.¹ Paradoxically, the mortality burden of cancer will increase due to population growth, decreases in deaths from other causes, and longer life expectancy with cancer, especially in poor and moderately resourced countries.

The proportion of cancer cases diagnosed in low- and middle-income countries increases continually. This is a combined result of population growth, aging trends, and lower mortality rates from infectious disease.^{2,3} While developing countries accounted for 15% of new cancer diagnoses in 1970, this proportion had risen to 56% by 2008² and is projected to reach 70% by 2030.^{2,4,5} Already nearly two thirds of the world's an-

nual 7.6 million deaths from cancer occur in low- and middle-income countries.^{2,5} Across the less well-resourced countries, and between low-income and high-income countries, there are substantial variations in the availability of diagnostic and treatment facilities to manage cancer and its human impact.

Even greater is the contrast in supportive, palliative, and terminal care resources available in high-income versus low-income countries—though not all affluent countries boast excellent end-of-life care. The quality-of-death index, a ranking of end-of-life care around the world conducted by The Economist Intelligence Unit, varies considerably across countries, with several well-resourced countries (eg, Italy, Finland, South Korea) ranking low on the overall scale.⁶ The goals of cancer care agreed upon in the global arena include improvement of outcomes for patients and their caregivers and reduction in the aggregate burden of suffering. A greater impact from limited healthcare resources might be achieved by allocating some of those toward palliation and, specifically, incorporating palliative care into routine oncology practice.

PALLIATIVE CARE: AN INTEGRAL COMPONENT OF CANCER CARE?

Cancer control is built on four fundamental pillars: prevention, treatment, cure, and palliation (Table 1). In each, there is a need for further progress to combat cancer globally. Yet while significant improvements have been made in the first three, with a corresponding evidence base developed to disseminate and sustain those improvements, progress in applying existing

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Original Article

Hospice Enrollment and Pain Assessment and Management in Nursing Homes

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 Brown University School of Medicine, Providence, Rhode Island, USA

Abstract

This study compared pain assessment and management in the last 48 hours of life for hospice and nonhospice nursing home residents. Included were 209 hospice and 172 nonhospice residents in 28 nursing homes in six geographic areas. Hospice patients were considered short-stay (seven days or less) ($n = 51$), or longer-stay (over seven days) ($n = 158$). Of residents not in a hospital or a coma ($n = 265$), 33% of nonhospice residents, 6% of short-stay and 7% of longer-stay hospice residents had no documented pain assessment ($P < 0.05$). For those with pain documented ($n = 93$), longer-stay hospice residents, compared to nonhospice residents, had a significantly greater likelihood of having received an opioid (adjusted odds ratio [AOR] 5.4; 95% CI 1.3, 21.7), and an opioid at least twice a day (AOR 2.7; 95% CI 0.9, 7.7; $P = 0.07$). Study results suggest that hospice enrollment improves pain assessment and management for nursing home residents; they also document the need for continued improvement of pain management in nursing homes. J Pain Symptom Manage 2003;26:791-799. © 2003 U.S. Cancer Pain Relief Committee. Published by Elsevier Inc. All rights reserved.

Key Words

Hospice, nursing home, pain assessment, pain management, end-of-life

Introduction

Although cancer and nonmalignant pain can be effectively treated,¹⁻⁴ with the option of terminal sedation as the last resort for selected patients with advanced disease,^{5,6} pain and symptom management in nursing homes is less than optimal.⁷⁻¹¹ Studies have shown that nursing home physicians often fail to identify pain as a problem, or to prescribe adequate pharmacological treatment for nursing home

residents.^{7,11-14} Additionally, when analgesics are prescribed in nursing homes, the medications used are often inconsistent with, and contrary to, recommended pain management for older adults.^{12-15,22}

Because U.S. nursing homes are increasingly the site of death,^{15,16} high-quality pain assessment and management in nursing homes is critical to the provision of high-quality end-of-life care to older Americans. When end-of-life care is provided by nursing homes in collaboration with hospices, an opportunity exists to optimize this care for the growing numbers of older adults dying in nursing homes. However, while 24% of all hospice beneficiaries in five states were estimated to reside in nursing homes, only 6% of nursing home residents who died from

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Does Receipt of Hospice Care in Nursing Homes Improve the Management of Pain at the End of Life?

Susan C. Miller, PhD, Vincent Mor, PhD, Ning Wu, MS, Pedro Gozalo, PhD, and Kate Lapane, PhD

OBJECTIVES: To compare analgesic management of daily pain for dying nursing home residents enrolled and not enrolled in Medicare hospice.

DESIGN: Retrospective, comparative cohort study.

SETTING: Over 800 nursing homes in Kansas, Maine, Mississippi, New York, and South Dakota.

PARTICIPANTS: A subset of residents with daily pain near the end of life taken from a matched cohort of hospice (2,644) and nonhospice (7,929) nursing home residents who had at least two resident assessments (Minimum Data Sets (MDSs)) completed, their last between 1992 and 1996, and who died before April 1997. The daily pain subset consisted of 709 hospice and 1,326 nonhospice residents.

MEASUREMENTS: Detailed drug use data contained on the last MDS before death were used to examine analgesic management of daily pain. Guidelines from the American Medical Directors Association (AMDA) were used to identify analgesics not recommended for use in managing chronic pain in long-term care settings. The study outcome, regular treatment of daily pain, examined whether patients received any analgesic, other than those not recommended by AMDA, at least twice a day for each day of documented daily pain (i.e., 7 days before date of last MDS).

RESULTS: Fifteen percent of hospice residents and 23% of nonhospice residents in daily pain received no analgesics (odds ratio (OR) = 0.57, 95% confidence interval (CI) = 0.45–0.74). A lower proportion of hospice residents (21%) than of nonhospice residents (29%) received analge-

sics not recommended by AMDA (OR = 0.65, 95% CI = 0.52–0.80). Overall, acetaminophen (not in combination with other drugs) was used most frequently for nonhospice residents (25% of 1,673 prescriptions), whereas morphine derivatives were used most frequently for hospice residents (30% of 1,058 prescriptions). Fifty-one percent of hospice residents and 33% of nonhospice residents received regular treatment for daily pain. Controlling for clinical confounders, hospice residents were twice as likely as nonhospice residents to receive regular treatment for daily pain (adjusted odds ratio = 2.08, 95% CI = 1.68–2.56).

CONCLUSION: Findings suggest that analgesic management of daily pain is better for nursing home residents enrolled in hospice than for those not enrolled in hospice. The prescribing practices portrayed by this study reveal that many dying nursing home residents in daily pain are receiving no analgesic treatment or are receiving analgesic treatment inconsistent with AMDA and other pain management guidelines. Improving the analgesic management of pain in nursing homes is essential if high-quality end-of-life care in nursing homes is to be achieved. *J Am Geriatr Soc* 50:507–515, 2002.

Key words: nursing homes; hospice; pain management; analgesics

The prevalence of unrelieved pain is disturbingly high in nursing homes.^{1–4} Considering that pain intensity increases as death nears⁵ and that more than 20% of older adults in the United States die in nursing homes,⁶ adequate pain management for dying nursing home residents is critical to achieving high-quality end-of-life care.

Most persons with cancer pain and nonmalignant pain can have their pain effectively treated,^{7–10} with the option of terminal sedation as the last resort.^{11,12} Still, nursing home physicians often fail to identify pain as a problem or to prescribe adequate pharmacological treatment for nursing home residents.^{1–4,10,13,14} Additionally, when analgesics are prescribed in nursing homes, the medications used are often inconsistent with, and contrary to, recommended pain management for older adults.¹³ Recognizing the need for improved pain management in nursing

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Hospital based palliative care teams improve the symptoms of cancer patients

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Abstract: Despite the increase in hospital palliative care teams, there is little research into their impact on symptom control in patients. A nonequivalent control group design, using a quota sample, investigated 100 cancer patients who had been admitted to hospital for symptom control. Fifty patients received hospital palliative care team intervention compared with 50 patients receiving traditional care. Data was collected using the Palliative Care Assessment (PACA) symptom assessment tool on three occasions. Both groups showed a statistically significant improvement in their symptoms. This significance failed to meet the criterion of one point on a four point scale and therefore results have to be interpreted with caution. However the intervention group had a greater improvement in all their symptoms, particularly for the pain and anorexia for which there were no differences between the groups on the initial assessment, there was a statistically greater improvement for the intervention group ($P < 0.001$). Consecutive patients with cancer admitted to hospital for symptom control during this study improved, but those patients who received specialist palliative care had a significantly greater improvement in their symptoms. *Palliative Medicine* 2003; 17: 498–502

Key words: hospital palliative care teams; symptom control

Introduction

Approximately 56% of cancer patients in England and Wales die in hospital.¹ The increasing age of the population, smaller nuclear families unable to provide homecare and the increased use of medical technology to prolong life suggests this trend is likely to persist.² Despite this it is agreed that death in hospital is generally badly managed.³ Most dying patients suffer uncontrolled symptoms including pain, nausea, vomiting, constipation, anorexia and dyspnoea.^{3–6} In response, hospital based palliative care teams, have been developed to transfer the principles of hospice care to the acute setting.^{4–11}

Palliative care teams improve symptom control in patients with cancer.^{2,12,13} However, despite an increase in the number of hospital based teams, there is little research that evaluates their effectiveness.^{2,9} Three UK studies,^{6,9,14} and a recent systematic review² have all reported an improvement in symptom control, yet there is a lack of comparative studies with traditional treat-

ment.² The aim of this study was to determine whether the hospital based palliative care team had a greater effect on improving cancer patients' symptoms when compared to with standard care alone.¹⁵

Method

Study location and sample

The study took place in a large general (1300 beds) NHS hospital in the northwest of England and involved all patients with a confirmed diagnosis of cancer who were admitted to hospital for symptom control. (No distinction was made for patients who had advanced cancer, as the focus of the study was on symptom control). Access to patients was made by daily contact with the palliative care team or via the hospital bed management team. Patients unable to give informed consent, who were admitted with an unrelated medical problem, or were asymptomatic, were excluded from the study. Consecutive recruitment of all patients (who met the inclusion criteria) to both groups were made by one researcher (BJ).

The sample size was calculated from an estimate of the likely differences in symptom control between the nonequivalent groups. A significant difference was defined as one unit on a four point scale, within the various

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Comparing the Quality of Death for Hospice and Non-Hospice Cancer Patients

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AND ROBERT J. BAUGHER, PHD

In this secondary analysis of data from the National Hospice Study (NHS), a new measure, quality of death (QOD), was developed by weighting reports of cancer patients' last 3 days of life by what patients wanted their last 3 days to be like. Using analysis of covariance, the QOD scores were higher for terminally ill patients in hospices (either home-care [HC] or hospital-based [HB]) than similar patients who received conventional care (CC). The results are discussed in terms of verification of the hospice philosophy and other uses for a quality of death measure. Key words: hospice; terminal care; terminal illness; death and dying; quality of life; quality of care; cancer; measurement. (Med Care 1988; 26:177-182)

The philosophy of hospice care for dying patients and their families has been described extensively.¹⁻⁴ Hospice programs include palliative care and symptom control; individualized care for the dying patient; choices about treatment and place of death; use of professionals and volunteers in an interdisciplinary care team; supportive care for the family during the dying process and bereavement counseling after death; and maximum accessibility to care regardless of time of day or ability to pay. In contrast, conventional American health care for the terminally ill promotes aggressive rather than palliative care; is directed by a physician with limited input from other health-

care professionals; focuses treatment on only the identified patient; generally ceases to provide services after death occurs; and varies greatly in quality depending upon the financial resources of the patient and the time at which services are most needed. Because of the differences in these two systems of care, hospice advocates have suggested that hospice care provides—for those who want it—a better way of dying than that provided by the conventional American health-care delivery system.

Several studies have been conducted to test this assertion. The findings to date are at best equivocal. In the National Hospice Study (NHS) follow-up sample of 1,754 patients in 26 home-care hospices, 14 hospital-based hospices and 12 conventional-care sites, a major question addressed was whether hospice care produced a differential impact on the quality of life of terminally ill cancer patients compared with those in conventional care. In this study, quality of life was defined along several di-

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Terminal Care

A RANDOMISED CONTROLLED TRIAL OF HOSPICE CARE

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Abstract

Terminally ill cancer patients at a Veterans Administration hospital were randomly assigned to receive hospice or conventional care. The hospice care was provided both in a special inpatient unit and at home. 137 hospice patients and 110 control patients and their familial care givers (FCGs) were followed until the patient's death. No significant differences were noted between the patient groups in measures of pain, symptoms, activities of daily living, or affect. Hospice patients expressed more satisfaction with the care they received; and hospice patients' FCGs, showed somewhat more satisfaction and less anxiety than did those of controls. Hospice care was not associated with a reduced use of hospital inpatient days or therapeutic procedures and was at least as expensive as conventional care.

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A Randomized Trial of the Cost Effectiveness of VA Hospital-Based Home Care for the Terminally Ill

Susan L. Hughes, Joan Cummings, Frances Weaver, Larry Manheim, Barbara Braun, and Kendon Conrad

All admissions to a 1,100-bed Department of Veterans Affairs (VA) hospital were screened to identify 171 terminally ill patients with informal caregivers who were then randomly assigned to VA hospital-based team home care (HBHC, N = 85) or customary care (N = 86). Patient functioning, and patient and caregiver morale and satisfaction with care were measured at baseline, one month, and six months. Health services utilization was monitored over the six-month study period and converted to cost. Findings included no differences in patient survival, activities of daily living (ADL), cognitive functioning, or morale, but a significant increase in patient ($p = .02$) and caregiver ($p = .005$) satisfaction with care at one month. A substitution effect of HBHC was seen. Those in the experimental group used 5.9 fewer VA hospital days ($p = .03$), resulting in a \$1,639 or 47 percent per capita saving in VA hospital costs ($p = .02$). As a result, total per capita health care costs, including HBHC, were \$769 or 18 percent (n.s.) lower in the HBHC sample, indicating that expansion of VA HBHC to serve terminally ill veterans would increase satisfaction with care at no additional cost.

Supported by the Health Services Research and Development Services of the Department of Veterans Affairs.

Susan L. Hughes, D.S.W., Frances Weaver, Ph.D., and Kendon Conrad, Ph.D. are affiliated with the Department of Veterans Affairs, Health Services Research and Development (HSR&D) Field Program, Edward Hines, Jr. VA Hospital, Hines, IL, and the Center for Health Services and Policy Research, Northwestern University, Evanston, IL. Joan Cummings, M.D. and Barbara Braun, Ph.D. are with the HSR&D Field Program, Edward Hines, Jr. VA Hospital; and Larry Manheim, Ph.D. is with the Center for Health Services and Policy Research at Northwestern University. Address correspondence and requests for reprints to Susan L. Hughes, D.S.W., Director, Program in Gerontological Health, Center for Health Services and Policy Research, Northwestern University, 629 Noyes Street, Evanston, IL 60208. This article, submitted to *Health Services Research* on August 29, 1990, was revised and accepted for publication on March 8, 1991.

Effectiveness of a Home-Based Palliative Care Program for End-of-Life

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and DAVID A. CHERIN, Ph.D.^{2,4}

ABSTRACT

Context: Despite the widespread recognition of the need for new models of care to better serve patients at the end-of-life, little evidence exists documenting the effectiveness of these models.

Objective: To evaluate the effectiveness of a palliative program for end-of-life care.

Design: A comparison group study was conducted between March 1999 and August 2000 comparing subjects enrolled in a palliative care intervention to those receiving usual care.

Setting: Home Health Department at Kaiser Permanente, TriCentral Service Area.

Subjects: During the course of the 2-year study, 558 subjects were enrolled. A subgroup of 300 patients who had died during the course of the study was selected for analysis; 161 were enrolled in the Palliative Care Program and 139 in the comparison group.

Intervention: The Kaiser Permanente Palliative Care Project is a multidisciplinary care management approach for home-based end of life care and treatment. The program is designed to facilitate the transition from acute to palliative care during the last 12 months of life with the goal of improving quality of life through the provision of symptom control and pain relief, emotional and spiritual support, and patient education.

Main outcome measures: Medical service use and satisfaction with services.

Results: Palliative care patients had increased satisfaction with services at 60 days after enrollment and significantly fewer emergency department visits, hospital days, skilled nursing facility days, and physician visits than those in the comparison group. Those enrolled in palliative care averaged a 45% decrease in costs as compared to usual care patients.

Conclusion: Through integrating palliative care into curative care practices earlier in the disease trajectory, chronically ill patients nearing the end of life report improved satisfaction with care and demonstrate less acute care use resulting in lower costs of care. In addition, patients enrolled in the palliative care program were more likely to die at home than comparison group patients.

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This project was funded by a grant from the Garfield Memorial Fund from January, 1999 through December, 2000.

Reference 21

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J Pain Symptom Manage. 2003 Feb;25(2):150-68.

Is there evidence that palliative care teams alter end-of-life experiences of patients and their caregivers?

Higginson IJ, Finlay IG, Goodwin DM, Hood K, Edwards AG, Cook A, Douglas HR, Normand CE.

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Abstract

Palliative care provision varies widely, and the effectiveness of **palliative** and hospice **care teams** (PCHCT) is unproven. To determine the effect of PCHCT, 10 electronic databases (to 2000), 4 relevant journals, associated reference lists, and the grey literature were searched. All PCHCT evaluations were included. Anecdotal and case reports were excluded. Forty-four studies evaluated PCHCT provision. **Teams** were home **care** (22), hospital-based (9), combined home/hospital **care** (4), inpatient units (3), and integrated **teams** (6). Studies were mostly Grade II or III quality. Funnel plots indicated slight publication bias. Meta-regression (26 studies) found slight positive effect, of approximately 0.1, of PCHCTs on patient outcomes, independent of team make-up, patient diagnosis, country, or study design. Meta-analysis (19 studies) demonstrated small benefit on patients' pain (odds ratio [OR]: 0.38, 95% confidence interval [CI]: 0.23-0.64), other symptoms (OR: 0.51, CI: 0.30-0.88), and a non-significant trend towards benefits for satisfaction, and therapeutic interventions. Data regarding home deaths were equivocal. Meta-synthesis (all studies) found wide variations in the type of service delivered by each team; there was no discernible difference in outcomes between city, urban, and rural areas. **Evidence** of benefit was strongest for home **care**. Only one study provided full economic cost-benefit evaluation. This is the first study to quantitatively demonstrate benefit from PCHCTs. Such comparisons were limited by the quality of the research.

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Publication Types, MeSH Terms

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Family Perspectives on End-of-Life Care at the Last Place of Care

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OVER THE PAST CENTURY, DYING has become increasingly institutionalized. In the early 1900s most people died at home, but by the middle of the 20th century the majority of deaths in industrialized nations occurred in health care institutions. With recent changes in health care, society is struggling with the role that governmental and nongovernmental regulatory structures should play in assuring that the health care system provides competent, coordinated, and compassionate care at life's end.¹

Early efforts to define a "good death" were based on expert opinion.²⁻⁴ Recent attempts have used focus groups and in-depth interviews to capture patient and family perspectives.⁵⁻⁷ Several authors of the current study developed a conceptual model of quality of end-of-life care⁷ with input from dying patients, their families, structured review of professional guidelines, and experts. This research indicates that high-quality end-of-life care results when health care professionals (1) ensure desired physical comfort and emotional support, (2) promote shared decision making, (3) treat the dying person with respect, (4) provide information and emotional support to family members, and (5) coordinate care across settings. Outcome

Context Over the past century, nursing homes and hospitals increasingly have become the site of death, yet no national studies have examined the adequacy or quality of end-of-life care in institutional settings compared with deaths at home.

Objective To evaluate the US dying experience at home and in institutional settings.

Design, Setting, and Participants Mortality follow-back survey of family members or other knowledgeable informants representing 1578 decedents, with a 2-stage probability sample used to estimate end-of-life care outcomes for 1.97 million deaths from chronic illness in the United States in 2000. Informants were asked via telephone about the patient's experience at the last place of care at which the patient spent more than 48 hours.

Main Outcome Measures Patient- and family-centered end-of-life care outcomes, including whether health care workers (1) provided the desired physical comfort and emotional support to the dying person, (2) supported shared decision making, (3) treated the dying person with respect, (4) attended to the emotional needs of the family, and (5) provided coordinated care.

Results For 1059 of 1578 decedents (67.1%), the last place of care was an institution. Of 519 (32.9%) patients dying at home represented by this sample, 198 (38.2%) did not receive nursing services; 65 (12.5%) had home nursing services, and 256 (49.3%) had home hospice services. About one quarter of all patients with pain or dyspnea did not receive adequate treatment, and one quarter reported concerns with physician communication. More than one third of respondents cared for by a home health agency, nursing home, or hospital reported insufficient emotional support for the patient and/or 1 or more concerns with family emotional support, compared with about one fifth of those receiving home hospice services. Nursing home residents were less likely than those cared for in a hospital or by home hospice services to always have been treated with respect at the end of life (68.2% vs 79.6% and 96.2%, respectively). Family members of patients receiving hospice services were more satisfied with overall quality of care: 70.7% rated care as "excellent" compared with less than 50% of those dying in an institutional setting or with home health services ($P < .001$).

Conclusions Many people dying in institutions have unmet needs for symptom amelioration, physician communication, emotional support, and being treated with respect. Family members of decedents who received care at home with hospice services were more likely to report a favorable dying experience.

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measures based on each of these domains have been developed and validated.⁸ The goal of this study was to use these measures to provide national esti-

mates of the dying experience and to examine whether family members' perceptions of the quality of end-of-life care differed by the last place of care.

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The health impact of health care on families: a matched cohort study of hospice use by decedents and mortality outcomes in surviving, widowed spouses

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Abstract

Alternative ways of caring for seriously ill patients might have implications not only for patients' own outcomes, but also, indirectly, for the health outcomes of their family members. Clinical observation suggests that patients who die "good deaths" may impose less stress on their spouses. Consequently, we sought to assess whether hospice use by a decedent is associated with decreased risk of death in surviving, bereaved spouses. We conducted a matched retrospective cohort study involving a population-based sample of 195,553 elderly couples in the USA. A total of 30,838 couples where the decedent used hospice care were matched using the propensity score method to 30,838 couples where the decedent did not use hospice care. Our principal outcome of interest was the duration of survival of bereaved widow/ers. After adjustment for other measured variables, 5.4% of bereaved wives died by 18 months after the death of their husband when their deceased husband did not use hospice and 4.9% died when their deceased husband did use hospice, yielding an odds ratio (OR) of 0.92 (95% CI: 0.84–0.99) in favor of hospice use. Similarly, whereas 13.7% of bereaved husbands died by 18 months when their deceased wife did not use hospice, 13.2% died when their deceased wife did use hospice, yielding an OR of 0.95 (95% CI: 0.84–1.06) in favor of hospice use. Our findings suggest a possible beneficial impact of hospice—as a particularly supportive type of end-of-life care—on the spouses of patients who succumb to their disease. Hospice care might attenuate the ordinarily increased mortality associated with becoming widowed. This effect is present in both men and women, but it is statistically significant and possibly larger in bereaved wives. The size of this effect is comparable to the reductions in the risk of death seen in a variety of other modifiable risk factors in women. Health care may have positive, group-level health "externalities": it may affect the health not only of patients but also of patients' family members.

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Keywords: Externalities; Caregiving; Social networks; Marriage; Bereavement; Terminal care; USA

Introduction

Having a spouse fall ill or die are common events that have powerful implications for the individuals involved and for society. Caring for a sick spouse can have

deleterious health consequences; this "caregiver burden" effect is especially severe among women (Barusch & Spaid, 1989; Pruchno & Resch, 1989). Having a spouse die can significantly increase a person's risk of death; this "widow/er effect" is especially pronounced in men (Parkes, Benjamin, & Fitzgerald, 1969; Hesling & Szklo, 1981; Schaefer, Quesenberry, & Soora, 1995; Young, Benjamin, & Wallis, 1963; Cox & Ford, 1964; Welin, Tibblin, & Svardsudd, 1985; Lillard & Waite, 1995). Both the caregiver and widow/er effects are probably related to the loss of beneficial social support from a

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Specialized palliative care services are associated with improved short- and long-term caregiver outcomes

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Abstract

Goals of work The goal of this study was to evaluate, at a population level, the association between specialized palliative care services (SPCS) and short- and long-term caregiver outcomes.

Patients and methods The Health Omnibus Survey, a face-to-face survey conducted annually in South Australia since 1991, collects health-related data from a rigorously derived, representative sample of 4,400 households. This study included piloted questions in the 2001, 2002, and 2003 Health Omnibus Survey on the impact of SPCS. Sample size was 9,088 individuals. “Unmet needs,” a short-term outcome relevant to the caregiving period during a life-limiting illness, were tallied. “Moving on,” a long-term

caregiver-defined outcome reflecting the caregiver’s adaptation and return to a new equilibrium after the death, was assessed with and without SPCS.

Results Thirty-seven percent (3,341) indicated that someone close to them had died of a terminal illness in the preceding 5 years, of whom 949 (29%) reported that they provided care. SPCS were involved in caring for 60% of deceased patients. Day-to-day caregivers indicated fewer unmet needs when SPCS were involved ($p=0.0028$). More caregivers were able to “move on” with their lives when SPCS were involved than when SPCS were not involved (86 vs 77%, $p=0.0016$); this effect was greatest in the first 2 years after the loved one’s death.

Conclusion At a population level, SPCS were associated with meaningful improvements in short-term (“unmet needs”) and long-term (“moving on”) caregiver-defined outcomes.

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Keywords Palliative care · Caregivers · Outcome assessment (health care) · Health services needs and demands

Introduction

In the more than 7,300 specialized palliative-care services (SPCS) internationally [6], a variety of models of service delivery are in place [42]. A common model of SPCS relies on trained specialist providers, whose work is largely in palliative care; in this model, coordination of care occurs wherever the patient is located.

To date, evaluation of SPCS has been difficult [1, 28]. A recent meta-analysis demonstrated that SPCS had a positive impact on patients’ pain, other symptoms, and caregiver satisfaction. Evidence is lacking for other caregiver outcomes, or for economic benefit to justify the community’s healthcare investment in these services [31].

Delivery strategies to optimize resource utilization and performance status for patients with advanced life-limiting illness: Results from the "Palliative Care Trial" [ISRCTN81117481]

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ABSTRACT

Background

Evidence-based approaches to improve delivery of specialized palliative care are needed.

Methods

This 2x2x2 factorial cluster-randomized controlled trial was conducted at an Australian community-based palliative care service, allowing three simultaneous comparative effectiveness studies. Participating patients were newly referred adults, experiencing pain, expected to live >48 hours. Patients enrolled with their general practitioners (GPs), and were randomized three times (1) individualized interdisciplinary case conference including their GP vs. control; (2) educational outreach visiting for GPs about pain management vs. control; and, (3) structured educational visiting for patients/caregivers about pain management vs. control; the control condition was current palliative care. Outcomes included Australia-modified Karnofsky performance status (AKPS) and pain from 60 days post-randomization, and hospitalizations.

Results

461 participants: mean age 71; 50% male; 91% cancer; median survival 179 days; median baseline AKPS, 60. Only 47% of individuals randomized to the case conferencing intervention received it; based upon a priori defined analyses, 32% of participants were included in final analyses. Case conferencing reduced hospitalizations by 26% [least square means hospitalizations per patient: case conference, 1.26 (standard error, SE, 0.10) vs. control 1.70 (SE 0.13), $p=0.0069$] and better maintained performance status [AKPS case conferences, 57.3 (SE 1.5) vs. control 51.7 (SE 2.3),

Palliative Care Trial Main Results

$p=0.0368$]. Among patients with declining function (AKPS<70), case conferencing and patient/caregiver education better maintained performance status [AKPS case conferences, 55.0 (SE 2.1) vs. control 46.5 (SE 2.9), $p=0.0143$; patient/caregiver education, 54.7 (SE 2.8) vs. control 46.8 (SE 2.1); $p=0.0206$]. Pain was unchanged. GP education did not change outcomes.

Conclusions

A single case conference added to current specialized community-based palliative care reduced hospitalizations and better maintained performance status. Comparatively, patient/caregiver education was less effective; GP education was not effective.

Effect of a palliative home care team on hospital admissions among patients with advanced cancer

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Abstract: This was a quasi-experimental study designed to determine whether, in patients with advanced cancer, a palliative home care team (PHCT) modified hospital utilization in the last six months before death. Of 2503 cancer deaths in the municipality of Genoa, Italy, in 1991, 189 (7.5%) received care from a PHCT. Three hundred and seventy-eight controls matched for primary tumour were selected. The groups were similar in terms of age, gender and most other demographic variables, except that educational level was lower, and times to death, from first diagnosis and from diagnosis of advanced or metastatic cancer, were longer among PHCT patients compared with the controls. Before referral to a PHCT, or a matched time in controls, both groups spent about 15% of days in hospital. After admission to a PHCT, the percentages of days in hospital increased in both groups as death approached, but it was much higher in the control group (30.3%; 95% confidence interval (CI): 26–34) than in the PHCT group (19.0%; 95% CI: 15–23). The difference between groups was most marked in the last month of life, and disappeared among those patients who were in care for more than 120 days (throughout the course of their illness). We conclude that a PHCT appears to reduce days in hospital and allows patients to spend more time at home. Differences in time in care between groups requires further investigations. *Palliative Medicine* 2003; 17: 315–321.

Key words: cancer; effectiveness; evaluation; home care; palliative care

Introduction

One benefit of palliative home care teams (PHCTs) is that they enable patients to remain at home for longer, by controlling symptoms and other problems and supporting the patient, family and professionals. This more closely meets the wishes of many patients and families,¹ and may be more cost effective.² However, contradictory or limited evidence has been shown by randomized controlled trials and quasi-experimental studies,^{3–6} except for a meta-analysis of home care that included a range of services.⁷

The first trial of a PHCT by Zimmer *et al.*,^{8,9} later replicated by Hughes *et al.*,¹⁰ in the USA found a reduction in time in hospital and an associated reduction in costs for patients in the care of home care teams. Data from the National Hospice Study, using a quasi-experi-

mental design supported this.^{11–13} However, a multi-centre randomized controlled trial of home care support in the USA found a reduction in hospital readmission at six months but not at 12 months, and higher costs.¹⁴

American PHCTs and hospice programmes, unlike European palliative services, provide all components of patient and family care. Thus, findings from American services may not be relevant to other countries.¹⁵ Early work by Parkes in the UK found an eightfold reduction in hospital days and costs following the introduction of a PHCT.¹⁶ Other results were more equivocal.^{17–19} Some did not assess multiprofessional PHCTs, but rather other models of care. Comparative evaluations of PHCTs in European countries outside the UK are rare.^{15,20,21} However, differences in culture and healthcare organization between countries means that such evaluation is urgently needed to understand the best ways to develop palliative care in Europe. A recent evaluation in Catalonia found that a PHCT reduced hospitalization and costs in the last month of life, but recommended that further work was needed to assess its effects on hospitalization over a longer period, ideally from the onset of palliative treatment to death.²²

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NHPCC Original Article

Comparing Hospice and Nonhospice Patient Survival Among Patients Who Die Within a Three-Year Window

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National Hospice and Palliative Care Organization (S.R.C., C.S.), Alexandria, Virginia; and Milliman, Inc. (B.P., K.F., K.I.), New York, New York, USA

Abstract

There is a widespread belief by some health care providers and the wider community that medications used to alleviate symptoms may hasten death in hospice patients. Conversely, there is a clinical impression among hospice providers that hospice might extend some patients' lives. We studied the difference of survival periods of terminally ill patients between those using hospices and not using hospices. We performed retrospective statistical analysis on selected cohorts from large paid claim databases of Medicare beneficiaries for five types of cancer and congestive heart failure (CHF) patients. We analyzed the survival of 4493 patients from a sample of 5% of the entire Medicare beneficiary population for 1998–2002 associated with six narrowly defined indicative markers. For the six patient populations combined, the mean survival was 29 days longer for hospice patients than for nonhospice patients. The mean survival period was also significantly longer for the hospice patients with CHF, lung cancer, pancreatic cancer, and marginally significant for colon cancer ($P = 0.08$). Mean survival was not significantly different (statistically) for hospice vs. nonhospice patients with breast or prostate cancer. Across groups studied, hospice enrollment is not significantly associated with shorter survival, but for certain terminally ill patients, hospice is associated with longer survival times. The claims-based method used death within three years as a surrogate for a clinical judgment to recommend hospice, which means our findings apply to cases where a clinician is very sure the patient will die within three years, and it points to the need to validate these findings. *J Pain Symptom Manage* 2007;33:238–246. © 2007 U.S. Cancer Pain Relief Committee. Published by Elsevier Inc. All rights reserved.

Key Words

Survival, hospice, palliative care, cancer, congestive heart failure

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Introduction

The purpose of hospice is to effectively provide palliative care to terminally ill patients and their families, which includes meeting patients' physical, social, spiritual, and emotional needs. The goal of hospice is neither to prolong life nor to hasten the dying process, but

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Special Article

Using National Health Policies to Improve Access to Palliative Care Medications in the Community

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Abstract

Access to affordable priority palliative care medicines needs to be informed by good clinical data from well-conducted clinical trials designed to address efficacy, cost-effectiveness, and safety. Availability of priority palliative care symptom control medicines improves the provision of palliation in the place of patient's choice including the community. Within Australia, a National Medicines Policy and a Palliative Care Strategy endorsed by Federal and State and Territory health ministers have facilitated a process to improve the evidence for palliative clinical practice and, through this, improve community availability of key medications for people at the end of life. The initiative, coordinated by a working party under government auspices, has brought together medicine regulators, the pharmaceutical industry, government, policy makers, and clinicians. The brief was to improve availability of key palliative care medications within the current national drug regulatory and funding frameworks. The results to date include: a palliative care section within the Pharmaceutical Benefits Scheme generating the first ever patient-defined section; medicines not previously listed now available; commitment of AU\$9.46 M for a national multisite collaborative clinical study network to improve the evidence for clinical interventions in the palliative care setting through systematic investigation with rigorous Phase III and IV studies to inform registration and subsidy applications; and establishing a national Communication Network of the Palliative Care Medications Working Group for the health workforce and community to improve the quality use where improved access has been achieved. J Pain Symptom Manage 2009;37:395–402. © 2009 U.S. Cancer Pain Relief Committee. Published by Elsevier Inc. All rights reserved.

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The Australian Palliative Care Outcomes Collaboration (PCOC) – measuring the quality and outcomes of palliative care on a routine basis

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Abstract. Australia is leading the way in establishing a national system (the Palliative Care Outcomes Collaboration – PCOC) to measure the outcomes and quality of specialist palliative care services and to benchmark services across the country. This article reports on analysis of data collected routinely at point-of-care on 5939 patients treated by the first fifty one services that voluntarily joined PCOC. By March 2009, 111 services have agreed to join PCOC, representing more than 70% of services and more than 80% of specialist palliative care patients nationally. All states and territories are involved in this unique process that has involved extensive consultation and infrastructure and close collaboration between health services and researchers.

The challenges of dealing with wide variation in outcomes and practice and the progress achieved to date are described. PCOC is aiming to improve understanding of the reasons for variations in clinical outcomes between specialist palliative care patients and differences in service outcomes as a critical step in an ongoing process to improve both service quality and patient outcomes.

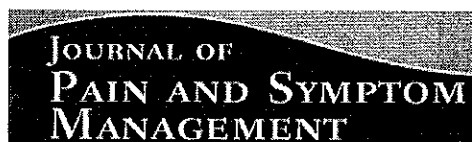
What is known about the topic? Governments internationally are grappling with how best to provide care for people with life limiting illnesses and how best to measure the outcomes and quality of that care. There is little international evidence on how to measure the quality and outcomes of palliative care on a routine basis.

What does this paper add? The Palliative Care Outcomes Collaboration (PCOC) is the first effort internationally to measure the outcomes and quality of specialist palliative care services and to benchmark services on a national basis through an independent third party.

What are the implications for practitioners? If outcomes and quality are to be measured on a consistent national basis, standard clinical assessment tools that are used as part of everyday clinical practice are necessary.

Governments across the developed world are increasingly grappling with how best to provide health care for people with life limiting illnesses¹ and how best to measure the quality and outcomes of that care.² Palliative care evolved as a speciality in Australia in the last three decades in response to the needs of people at the end of life and their families. Within health care, sub-specialisation was first offered by the Royal Australasian College of Physicians in 1987 and Australian Government funding of palliative care was included in the 1988 Australian

Health Care Agreement.³ In October 2000, the Australian Government released the *National Palliative Care Strategy: A National Framework for Palliative Care Service Development*,⁴ an important milestone as it was a consensus document signed by all states and territories. Funding to support the *Strategy* was provided through the *Australian Health Care Agreements 2003–2008*.⁵ Ministerial agreement was reached to improve the provision of palliative care service and to report national minimum data to the Department of Health



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Improving Outcomes for People With Progressive Cancer: Interrupted Time Series Trial of a Needs Assessment Intervention

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Accepted 27 April 2011, published online 03 January 2012.

Abstract

Context

Improving the effectiveness of cancer care delivery has become a major focus of research.

Objectives

This study assessed the uptake and impact of the Palliative Care Needs Assessment Guidelines and Needs Assessment Tool: Progressive Disease—Cancer (NAT: PD-C) on the outcomes of people with advanced cancer.

Methods

Given widely varying survival in people with advanced cancer, an interrupted time series design was used, with data on unmet needs, depression, anxiety, and quality of life collected from 195 patients using telephone interviews every two months, for up to 18 months. Patients completed at least two baseline interviews before health professionals were academically detailed in the use of the Palliative Care Needs Assessment Guidelines and NAT: PD-C. Health professionals completed the NAT: PD-C with patients approximately monthly for the remainder of the study. Changes in patients' outcomes were compared prior to and following the introduction of the NAT: PD-C using general estimating equations.

Results

Moderate to high needs across all domains were frequently seen in the preintervention phase. The use of the NAT: PD-C was associated with a significant reduction in health system and information and patient care and support needs.

Conclusion

These resources have the potential as an efficient and acceptable strategy for supporting needs-based cancer care. Further work is required to determine their unique contribution to improvements in patient outcomes.

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Gaps in the Evidence Base of Opioids for Refractory Breathlessness. A Future Work Plan?

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Abstract

Breathlessness or "shortness of breath," medically termed dyspnea, remains a devastating problem for many people and those who care for them. As a treatment intervention, administration of opioids to relieve breathlessness is an area where progress has been made with the development of an evidence base. As evidence in support of opioids has accumulated, so has our collective understanding about trial methodology, research collaboration, and infrastructure that is crucial to generate reliable research results for palliative care clinical settings. Analysis of achievements to date and what it takes to accomplish these studies provides important insights into knowledge gaps needing further research and practical insight into design of pharmacological and nonpharmacological intervention trials in breathlessness and palliative care. This article presents the current understanding of opioids for treating breathlessness, what is still unknown as priorities for future research, and highlights methodological issues for consideration in planned studies.

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Validity, reliability and clinical feasibility of a Needs Assessment Tool for people with progressive cancer

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Abstract

Background: Needs assessment is a valuable approach for determining the way health and social services allocate resources to people with cancer and their caregivers.

Aim: To assess the reliability, validity and acceptability of a Needs Assessment Tool (NAT) in a palliative care clinical setting.

Methods: Psychometric properties of the NAT were initially explored in a pilot study involving filmed simulated advanced cancer patient and caregiver consultations. Further testing was undertaken in a clinical setting to determine the inter-rater reliability, validity and feasibility of the NAT.

Results: The results of the pilot study suggested good reliability and acceptability in a simulated setting. Further testing indicated that the patient daily living item was positively correlated with the Resource Utilisation Groups—Activities of Daily Living ($r = 0.74$) and negatively correlated with the Australian Karnofsky Performance Scale ($r = -0.84$). Prevalence- and bias-adjusted kappa values also indicated adequate agreement between Palliative Care Problem Severity Score items and the patient physical item (0.48), psychological item (0.45) and caregiver well-being item (0.42).

Conclusions: Needs assessment not only facilitates the identification of people who have specific concerns or are dissatisfied with some aspect of their care, but also determines the person's desire for assistance and involvement with services. The NAT is a highly acceptable and efficient tool that can be used by health professionals with a range of clinical expertise to identify individuals' needs, thereby enabling a better match of interventions of specialist services more closely linked to needs.

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Keywords: cancer; palliative care; needs assessment; patient; caregiver

Introduction

Understanding the individual experiences and needs of people with cancer and their caregivers is essential to providing care that is explicitly and individually tailored. Articulated benefits of needs assessment include not only its potential for identifying issues that are not being addressed, but also to determine whether the person perceives these issues as a problem for which they require further assistance and the level of assistance they require [1–3]. A needs based approach to the delivery of cancer care has become an important focus, to ensure people receive care according to the complexity and severity of their needs, independent of diagnosis or prognosis [4]. However, as Carlson [5] suggests, implementing care based on the assessment of needs has its own challenges,

including how to define need and how and when to assess need. Therefore, the accurate assessment of these experiences and needs within the clinical setting continues to be a challenge.

Capturing information pertaining to a person's needs in an accurate and efficient manner has led to the development of a variety of needs assessment tools. Using a structured tool can prompt the discussion of issues between patients, families and health professionals [6,7], while providing a strategy for triaging people according to the degree of burden they experience as a result of their perceived unmet needs [2,8–10]. Tools can also assist institutions in prioritising resources and identifying areas that require improvement [7,8]. Unfortunately, many of the existing needs assessment tools have psychometric problems, including inadequate reliability, validity and responsiveness [7,9,11].

Palliative care in undergraduate curricula: Results of a national scoping study

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Abstract

Background: We wished to explore the ways in which palliative care is included in undergraduate health services curricula in Australia and the barriers to, and opportunities for, such inclusion.

Methods: A scoping study of current Australian undergraduate health care curricula, using an email survey of deans (or equivalent) of health faculties was designed utilising all Australian undergraduate courses that prepare medicine, nursing and allied health professionals for entry to practice. Participants were deans or faculty heads from health and related faculties which offered courses relevant to the project, identified from the Australian Government Department of Education, Science and Training website. Sixty-two deans (or equivalent) from 41 Australian

universities were surveyed. A total of 42 completed surveys were returned (68% of deans).

Main outcome measures were total hours, content, teaching and learning strategies and resources for palliative care education in undergraduate curricula; perceived gaps, barriers, and opportunities to support the inclusion of palliative care education in undergraduate curricula.

Results: Forty-five percent of respondents reported the content of current curricula reflected the palliative approach to a large degree. More than half of the respondents reported that their course had palliative care components integrated to a minor degree and a further third to a moderate degree. The number of hours dedicated to palliative care and teaching and learning strategies varied across all respondents, although there was a high degree of commonality in content areas taught.

Conclusion: Current Australian undergraduate courses vary widely in the nature and extent to which they provide education in palliative care.

Keywords: palliative care, palliative approach, undergraduate education, curriculum.

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Changes in the quantity and level of evidence of palliative and hospice care literature: the last century.

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Abstract

PURPOSE: To objectively quantify the literature and the clinical trial basis for palliative and hospice practice given a perception that its **evidence** base is not well developed.

METHODS: Using Ovid Medline, the study looked at cumulative and absolute numbers of articles in the general medical literature and the palliative and hospice care literature. The same comparisons were made exploring clinical trials from 1902 to 2005. Data were collated in five year groups from 1970 onward using a highly specific search phrase.

RESULTS: The proportion of all Ovid Medline publications relating to palliative and hospice care rose from 0.08% in 1970 to 0.38% of the literature in 2005. In the same time, clinical trials increased from 0.96% to 7.22% of the palliative care literature published. By 2005, one in every 122 clinical trials published in the literature as a whole was in palliative or hospice care. The rate of growth in palliative care clinical trials as a proportion of all palliative and hospice publications was on average 1.4 times greater than in the corresponding general literature. More than one half of these studies were reported in just 43 journals, most of which were not specialist palliative and hospice care journals.

DISCUSSION: Given the diversity of journals in which clinical studies related to hospice and palliative care appear, there is a key challenge for clinicians in finding ways that will allow currency of practice in a broad and rapidly changing field.

PMID: 19001326 [PubMed - Indexed for MEDLINE]

Publication Types, MeSH Terms

LinkOut - more resources

Key characteristics of palliative care studies reported in the specialized literature

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Abstract

Context

Although research activity in palliative care is rapidly increasing, the composition of published studies—in terms of significant research characteristics—has not yet been well described.

Methods

This sub-study of a larger bibliographic study describes the topics of, and funding for palliative care studies reported in the three hospice and palliative care journals with the highest impact factor (Journal of Pain and Symptom Management, Palliative Medicine, Journal of Palliative Medicine). The targeted journals were searched for 2007 using a previously validated OVID Medline filter for palliative care. All empirical palliative care studies were included. Papers were classified according to topics (palliative care patient, caregiver/family, health professional, service provision, tool development, healthy volunteer, medication compatibility, community), study type (intervention, non-intervention), country of origin and funding source (pharmaceutical company, other funder, unfunded).


Results

Of 409 citations identified, the search yielded 189 eligible papers. The majority of papers were descriptive/observational. Approximately half were unfunded. Caregivers, healthy volunteers and health service research were the least frequent topics for research. Only five randomised controlled trials were reported.

Discussion

While there is a broad range of research undertaken in palliative care, few studies generate high-level evidence with data showing a relative lack of funding for hospice and palliative care studies.

Collaborating or co-existing: a survey of attitudes of medical oncologists toward specialist palliative care

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Abstract

Patients with advanced cancer often have complex care needs requiring collaboration between medical oncology and palliative care providers. Little is known about how effective and acceptable such collaboration is to medical oncologists. Attitudes of Australian medical oncologists toward collaboration with specialist palliative care services were investigated using a Web-based survey. Descriptive statistics and attitude indices were calculated and a thematic content analysis performed. One hundred and fifteen respondents (78 medical oncologists, 37 trainees) completed the survey (response rate 30.3%). Positive attitudes toward specialist palliative care involvement were expressed with most respondents preferring concurrent rather than sequential models of care (94.8%, $n=109$). Reported barriers to collaboration included reluctance for referral by patients (minor 60.9%, $n=70$; major 8.7%, $n=10$) or families (minor 67%, $n=77$; major 7%, $n=8$), a lack of inpatient beds (minor 27%, $n=31$; major 34.8%, $n=40$) and inadequate resources for specialist palliative care to take some referrals (minor 30.4%, $n=35$; major 30.4%, $n=35$). There was no difference in attitude indices for those who had completed a palliative care rotation during their training (33%, $n=38$) and those who had not. Suggestions for improvement in collaboration focused around four areas – improved resources, improved multidisciplinary links, mutual respect and understanding, and consistency in service provision. This study is the first to specifically investigate the views of Australian medical oncologists toward collaboration with specialist palliative care. While positive attitudes have been expressed, identified barriers to collaboration need attention.

Keywords

medical oncology, palliative care, collaboration, health care survey, attitudes of health personnel

Introduction

Specialist palliative care (SPC) in Australia provides consultative and/or direct care for patients with a life-limiting illness, and support for their caregivers. It builds on the palliative approach of primary care providers, and provides a higher level of expertise in complex symptom control, grief and bereavement.^{1,2} Successful integration of SPC into the management of patients with advanced cancer is dependent on effective collaboration with cancer specialists.

While the attitudes of Australian general practitioners^{3,4} and haematologists⁵ to SPC have been

explored, less is known about the attitudes of medical oncologists toward collaboration with SPC despite the fact that approximately 85% of current referrals to SPC services in Australia are for patients with cancer.⁶ A survey of a diverse range of Australian sub-specialists caring for cancer patients (18.2% medical oncologists) revealed positive views about the involvement of SPC.⁷ Individual results, however, were not provided for the medical oncology group.

There have been three surveys exploring the attitudes of American Society of Medical Oncology (ASCO) members toward provision of and training in end of life

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Promoting patient centred palliative care through case conferencing

BACKGROUND

What are the characteristics of case conferences between general practitioners and specialised palliative care services (SPCS)?

METHODS

Study participants were adults (N=461) with pain in the preceding 3 months who were referred to a SPCS and their GPs (N=230). Patients were randomised to case conferences or routine care by SPCS.

RESULTS

One hundred and sixty-seven conferences were held; 46 patients withdrew and 142 died before the conference could be conducted. Medicare payment was requested for 72 (43%) conferences. Median time from randomisation to case conference was 52 days (SD: 55), and from case conference to death/end of study was 79 days (SD: 106). Twenty-five percent of conferences had over three health professionals participant; patients and/or their caregivers participated in 91%. Average conference duration was 39 minutes (SD: 13). Mean conference length did not increase when more health professionals were present (3 vs. >3, 39 [SD: 14] vs. 42 [SD: 11] minutes, $p=0.274$), nor when patients/caregivers were present (present vs. absent, 39 [SD: 13] vs. 44 [SD: 14] minutes, $p=0.159$).

DISCUSSION

Case conferencing involving SPCS, the GP, other health professionals and the patient can be an efficient part of routine care.

Palliative care focuses on optimising function and comfort for people with progressive life limiting illness.¹ It incorporates nursing, medical and allied health staff, therefore making the coordination of services crucial. When communication between health care providers is poor, effort may be duplicated.^{2,3} Multiprofessional teams provide better palliative care than practitioners working in isolation,^{4,5} and better coordination of existing services can decrease resource utilisation while still maintaining quality.⁶

Medicare Benefits Schedule (MBS) rebates for case conferencing were introduced in Australia in 1999 with the goal of shifting from short term episodic care to longitudinal planning for contingencies.⁷ Uptake of these case conference rebates has however been poor.⁸

Case conferencing can provide a funded mechanism to enhance coordination between a person with advanced life limiting illness, their general practitioner and the palliative care team. This was demonstrated in The Palliative Care Trial, a randomised controlled trial (RCT) conducted in Adelaide, South Australia.⁹

Methods

The study design and methodology were reported previously.⁹ Recruitment was conducted between April 2002 and May 2004. The case conferencing randomisation was 3:1. Participants were followed until death or the study end (November 2004). Main outcomes were integrated performance status,¹⁰ symptom control, palliative phase,¹¹ and resource utilisation.

Study setting

Trial participants were recruited through a regional multidisciplinary specialised palliative care service (SPCS) with more than 1100 referrals per year, 85% with cancer. The SPCS supports GPs providing primary palliative care in the region. The median time from referral to death for all patients referred to the service was 49 days, mean 121 days.

Study participants

Adult patients referred to the SPCS with any form of pain in the preceding 3 months were eligible; patients who did not live within the region, who were expected to die

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