Phase One of the National Palliative Care Research Program

Summary Paper

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Prepared by: **Professor David Currow and Ms Jennifer Tieman**
Department of Palliative and Supportive Services
Flinders University

Foreword

The development of research and evidence to support clinical practice, service delivery and policy development is an important component of health care. For an emerging discipline such as palliative care the evidence base to support best practice is still evolving.

Palliative care is a multidisciplinary field of practice. It provides care that improves the quality of life for patients with a life limiting illness and their families. Palliative care is provided in many settings and uses an interdisciplinary team approach to care.

In 2001, the Department of Health and Ageing in collaboration with the National Health and Medical Research Council (NHMRC) announced funding for a program of palliative care research (the National Palliative Care Research Program). The aim of the program was to fund research into palliative care that would inform policy development and improve clinical practice and service delivery. Eighty expressions of interest were submitted and twenty-seven full grant applications made. Following review, using the established NHMRC processes, thirteen projects were funded.

These thirteen projects looked at the following priority areas:

- Palliative care service delivery for rural and Indigenous communities
- Assessing the effectiveness of existing models of palliative care service delivery
- Refining the definitions and management of cachexia and its related symptoms, and
- Looking at the trajectory of the course of illness for end of life diseases other than cancer.

The results of the Research Program have been broad and far-reaching. Some projects have informed national guidelines relating to clinical practice. Other projects have provided important insights into how service delivery can be improved and how it can be assessed. Several projects have also highlighted the developing responsibilities of palliative care beyond cancer diagnoses.

While each individual project has contributed to the evidence and knowledge base for palliative care, the program itself has made a significant contribution to the development of the research infrastructure for palliative care. It has provided researchers and clinicians with an opportunity to not only participate in national level research but to extend their research expertise. The program has also highlighted the diversity of the research approaches that can be applied within palliative care. Finally, the National Palliative Care Research Program has accorded palliative care research a status that will contribute to and enhance its long-term development.

FOREWORD **2**

SECTION 1: BACKGROUND TO PHASE ONE OF THE NATIONAL PALLIATIVE CARE RESEARCH PROGRAM **4**

Palliative Care and the role of research 4
Background to the National Palliative Care Research Program 5
Overview of the application and selection process 6
Related Initiatives 7

SECTION 2: SUMMARY OF PROJECTS FUNDED **8**

1. The development of an innovative model for Indigenous palliative care service delivery 9
2. Development of a 'pop-up palliative care service': a new model to support palliative care delivery in rural and remote Australia 13
3. The investigation of an innovative telemedicine models to support palliative care delivery in rural and remote Australia 15
4. Assessment of the effectiveness of Australian models of palliative care delivery in four neuro-degenerative disorders 18
5. Palliative care constituency, utilisation and impact on health care: a Western Australian based epidemiological and sociological study 21
6. Early referral to palliative care: a randomised trial of patients with metastatic cancers and a survival expectation of less than 12 months 25
7. Body composition changes in cardiac cachexia: patho-physiology and quantification 27
8. Improve care of dying with chronic heart failure 29
9. Palliative care in aged care facilities for residents with a non-cancer diagnosis 32
10. Renal dialysis abatement: decision-making and social impact of transition to terminal care 35
11. Understanding factors contributing to nausea: clinical and patient perspectives 38
12. Objective assessment (based on whole body bio-impedance) of the trajectory of the course of illness for end of life non-cancer related diseases: biological, social and environmental determinants 40
13. Improving the management of nausea in advanced cancer: pragmatic tools for the assessment and treatment of nausea in clinical practice 43

SECTION 3: IMPLICATIONS FOR THE FIELD **46**

Value of the National Palliative Care Research Program 46
Overview of findings for practice and service delivery 46
Development of the research community 48
Implications for the future 48

REFERENCES **49**

APPENDIX A: MEMBERSHIP OF THE PALLIATIVE CARE RESEARCH WORKING COMMITTEE AND THE PALLIATIVE CARE RESEARCH COMMITTEE **50**

Palliative Care Research Working Committee 50
Palliative Care Research Committee 50

APPENDIX B: SUMMARY OF PUBLICATIONS AND PRESENTATIONS RELEVANT TO THE NATIONAL PALLIATIVE CARE PALLIATIVE RESEARCH PROGRAM **51**

Conference Presentations 51
Publications 52

Section 1: Background to Phase One of the National Palliative Care Research Program

Palliative Care and the role of research

Palliative care is a field of study and practice that is built around the concept of holistic care of a patient with a life-limiting illness and their family drawing on knowledge and skills found in many disciplines.

The World Health Organisation describes palliative care in the following way:
Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. Palliative care:

- *provides relief from pain and other distressing symptoms;*
- *affirms life and regards dying as a normal process;*
- *intends neither to hasten or postpone death;*
- *integrates the psychological and spiritual aspects of patient care;*
- *offers a support system to help patients live as actively as possible until death;*
- *offers a support system to help the family cope during the patient's illness and in their own bereavement;*
- *uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;*
- *will enhance quality of life, and may also positively influence the course of illness;*
- *is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.*

(http://www.who.int/cancer/palliative/definition/en/ Accessed 12 March 2005)

This definition recognises that many diseases have a terminal phase and that the principles and philosophy used in providing palliative care could be beneficially applied to diseases that are progressive in nature such as chronic obstructive pulmonary disease or dementia.

The use of research and evidence is playing an increasingly important role in the Australian health system to guide clinical practice, to develop national and jurisdictional/local palliative care policy and to determine the most effective methods of service delivery. Palliative care however is still a young discipline with an emerging evidence base. The first academic chair in palliative care was only appointed in the late 1980's. The academic base for palliative care is still developing with associated implications regarding the capacity to undertake specialist research in the field. At the same time the importance of using the best available evidence to drive decision making and clinical judgment has never been higher.

Australia confronts an ageing population and a changing demography of disease and illness. These will increase the importance of palliative care as the demand for services and the specialist knowledge relating to the care of those with life limiting illnesses grows. This will in turn drive the need for research to assist in decision-making.

Background to the National Palliative Care Research Program

The last decade has seen greater recognition by the state and federal governments as to role of palliative care in the Australian health system. The Kasap Report to the Palliative Care Program Review acknowledged the importance of the funding program begun in the 1993-4 financial year to the delivery of palliative care [1]. The associated reviews dealing with the principles supporting the delivery of holistic and multidisciplinary care services and performance indicators led to the development of three major papers:

- National Palliative Care Strategy [2],
- Background for A National Strategy for Palliative Care in Australia [3], and
- Performance Indicator Development in Palliative Care [4].

The development of the National Palliative Care Strategy (2000) articulated the essential ongoing role of palliative care within health care and highlighted the importance of research to the development of palliative care. The second goal of the National Strategy emphasized quality and effectiveness and included an objective and series of strategies focusing specifically on research.

Objective 2.5 of the National Palliative Care Strategy is
To promote, support and implement the results of ongoing research into client care needs, best practice palliative care, service delivery models and resource allocation models. [2] p20

Alongside the development of the National Strategy documents, the Department of Health and Ageing commissioned Palliative Care Australia (PCA) to undertake a scoping study to review current research in Australia, to identify priorities for palliative care research and to examine how palliative care research could be developed [5].

The study identified various strengths with regard to palliative care research in Australia, particularly:

- World class service delivery programs that could provide a base for research work
- A small but competent core of researchers
- A limited but significant base for research collaborations, and
- An openness to diversity and innovation in research.

There were, however, significant barriers to the development of research including:

- Historical and social barriers to do with researching death and dying
- Lack of a culture for enquiry and systematic evaluation within the palliative care community
- Lack of research programs, infrastructure and training programs
- Difficulties with geographic separation that impede collaboration
- Funding difficulties for palliative research
- The heavy clinical load of staff, and
- Methodological and ethical issues in undertaking palliative research.

Various topics and priorities for research were also examined.

Following the release of the PCA scoping study, the Department of Health and Ageing established a collaborative Research Program for palliative care to inform policy development and improve clinical practice. The National Health and Medical Research Council (NHMRC) agreed to administer this process.

The Research Program commenced under the auspices of the NHMRC's Strategic Research and Development Committee (SDRC). Responsibility for the Research Program passed to the Strategic Research Initiative Committee following the amalgamation of the SDRC and the NHMRC's Research Committee. Direct oversight of the National Palliative Care Research Program rested initially with the SDRC's subcommittee, the Palliative Care Research Working Committee, and subsequently with the working group of the Strategic Research Initiative Committee, the Palliative Care Research Committee. Membership of the Palliative Care Research Working Committee and the Palliative Care Research Committee can be found in Appendix A.

Four research priority areas were identified for the Research Program:

- Palliative care service delivery to rural areas
- Assessment of the effectiveness of existing models of palliative care services delivery
- Refining the definitions and management of cachexia and its related symptoms, and
- The trajectory of the course of illness for end of life disease, other than cancer, addressing either or both biological and social/environmental factors.

(http://www.nhmrc.gov.au/research/srdc/pallcare.htm Accessed 16 February 2005)

Overview of the application and selection process

To support the development of research capacity in palliative care, a capacity building workshop was held in early 2001. Forty-four people attended the workshop. The workshop concentrated on educating participants on NHMRC processes and effective application writing.

The selection process began with an expression of interest. Expressions of interest included the proposed methods with a rationale, an indicative budget and budget justification, an outline of anticipated outcomes, and information on the qualifications and experience of the researchers. Interdisciplinary and multisite collaborative research was encouraged. Shortlisted proposals were then invited to make a full grant application. Twenty-two attendees from the capacity building workshop submitted an expression of interest to the publicly announced grant program.

Eighty expressions of interest were received for the National Palliative Care Research Program of which 27 were shortlisted and invited to make a grant application. Following rigorous assessment using the standard peer-reviewed processes of the NHMRC, ten projects were approved in early 2002. These projects were to be conducted over two years. In October 2002, a further three projects dealing with cachexia/nausea research were approved with work to commence in early 2003.

These thirteen projects formed Phase One of the National Palliative Care Research Program. Of these thirteen projects, two of the projects' chief investigators had participated in the initial capacity building workshop.

Related Initiatives

Several further capacity building initiatives were undertaken as part of the National Palliative Care Research Program. Six Public Health (Palliative Care) Ph.D. scholarships were awarded in 2002. The specific topics of these six scholarships were as follows:

- Spirituality and coping in palliative care
- Ethics and culture in palliative care
- Transplant care settings and palliative care
- Scope of practice and role preparation of the Australian palliative care nurse practitioner
- Psychosocial processes of decision-making in palliative care, and
- Impact of cancer diagnosis and treatment on cancer patients and their families

A workshop followed by a “think tank” was held as part of the National Palliative Care Research Program. Participants of the workshop included those awarded grants and scholarships and other working in the palliative care research community. The workshop participants reviewed the barriers encountered in palliative care research and suggested ways to overcome them. The subsequent “think tank” identified some key methodological approaches to overcoming barriers to palliative care research.

Section 2: Summary of Projects Funded

Project Title	Status
Development of an innovative model for Indigenous palliative care	Completed
Development of a 'pop-up palliative care service': a new model to support palliative care delivery in rural and remote Australia	Completed
Investigation of an innovative telemedicine model to support palliative care delivery in rural and remote Australia	Completed
Assessment of the effectiveness of Australian models of palliative service delivery in four neurodegenerative disorders	Completed
Palliative care constituency, utilisation and impact on health care: a Western Australian based epidemiological and sociological study	Completed
Early referral to palliative care: a randomised trial of patients with metastatic cancers and a survival expectation of less than twelve months	Interim report. Data collection continuing.
Body composition changes in cardiac cachexia : patho-physiology and quantification	Completed
Improve care of the dying with chronic heart failure	Completed
Palliative care in aged care facilities for residents with non-cancer diagnosis	Completed
Renal dialysis abatement: decision-making and social impact of transition to terminal care	Completed
Understanding factors contributing to nausea: clinical and patient perspectives	Interim report Data collection continuing.
Improving the management of nausea in advanced cancer: pragmatic tools for the assessment and treatment of nausea in clinical practice	Interim report Data collection continuing.
Objective assessment (based on whole body bio-impedance) of the trajectory of the course of illness for end of life non-cancer related disease: biological, social and environmental determinants	Interim report Data collection continuing.

1. The development of an innovative model for Indigenous palliative care service delivery

Lead Chief Investigator:	Dr. Pam McGrath
Other Chief Investigators:	Prof Jenny Watson
Administering Organisation:	Charles Darwin University
Collaborating Institutions:	Central Queensland University Territory Health Service Palliative Care Unit
Funds granted:	$100 000

RATIONALE

Around 2% of Australia's population is Indigenous. However in the Northern Territory nearly 24% of the population is represented by Aboriginal and Torres Strait Islander peoples with lower percentages in the more populated states of Western Australia, South Australia and Queensland. While the majority of this population lives on or near accessible highways, a minority lives in remote areas that can be difficult to access. The provision of health care and palliative care in these areas can be challenging.

For Indigenous people morbidity and mortality remains high compared to non-Indigenous people. Palliative care for Indigenous Australians may occur at a much earlier age than for non-Indigenous Australians. Indigenous people will have different social and health needs based on culture, age and gender.

Previous research has highlighted issues and concepts such as cultural safety, Indigenous views on disease and health, differences in cultural beliefs and the need for community support. However, there is no framework or model that brings together the issues and concepts that underpin palliative care for the Indigenous population.

ORIGINAL AIMS

To propose and investigate innovative models for Indigenous palliative care service delivery.

Objectives:

1. To develop an analysis respectful of difference and complexity that incorporates factors associated with geographical setting, available resources, locality (rural and remote), links with specialist centres, and sociopolitical and professional infrastructure
2. To build an understanding of innovative models by evaluating and documenting successful services to Indigenous people that are currently providing leadership in the area
3. To understand the factors that need to be taken into consideration for the development of palliative care services for Indigenous people (where they do not exist), by documenting the obstacles to progress through feed-back gained by networking and collaborating with a range of Indigenous health care providers and consumers
4. To incorporate a multi-disciplinary approach that builds on the work already completed in the area with a national team of researchers who have

demonstrable expertise in rural research in collaboration with a representative range of rural organisations who have already made a commitment to the project, and

5. To explore provision of palliative care health service delivery in rural areas from the framework of the continuum of care that acknowledges that the treatment of serious illness for Indigenous patients is inextricably linked with specialist treatment in the metropolitan area.

Changes made to original aims

The original aim was to explore innovative models of palliative care health service delivery to rural areas looking at three specific areas (shared care, relocation and Indigenous care). The awarding of the grant required that the project focus specifically on Indigenous palliative care.

METHOD

The project utilised a multidisciplinary (nursing, general practice, social work, specialist medicine) collaboration of researchers (from Queensland, South Australia and the Northern Territory) and palliative care practitioners providing leadership in Indigenous health care.

The project consisted of three phases.

Phase one: Consultation and recruitment

This involved forming a reference group of key Indigenous and non-Indigenous stakeholders who advised regarding data collection tools. Information about the project was disseminated through existing networks and individuals, and communities were invited to participate.

Phase two: Data collection and analysis

An audit tool was developed. Internal audits were conducted with each of the collaborating palliative care services and relevant stakeholders. Data was also collected using taped interviews. The areas for data collection were determined with other concurrent research projects in Indigenous palliative care to prevent duplication. Interviews were conducted in four geographical areas in the Northern Territory.
Data from the audit was analysed using the statistical package, SPSS. Interview data was analysed using a specialist qualitative software program, NUD*IST.

Phase three: Model development, preparation and dissemination of the report

The model was developed and reviewed by both a national panel and a meeting of the Northern Territory Aboriginal Reference Group.

KEY FINDINGS

There are important principles that underpin service delivery in Indigenous care. They are:

- Cultural safety
- Equity in service delivery
- Autonomy
- Importance of trust

- Humane, non-judgmental care
- Seamless care
- Emphasis on living, and
- Respect.

The model that was developed is built around core concepts with an ultimate emphasis on advocacy at the local level. The heart of the model is the patient and extended family overlaid with the concept of cultural safety and affirming community participation, personal advocacy, choice and empowerment. The model then details by interlocking circles the varied practical elements that need to be addressed in Indigenous palliative care including:

- culturally appropriate health care facilities
- understanding/support of cultural practices
- addressing relocation issues with a focus on staying home
- consumer and professional education looking at cultural, cancer and palliative care issues
- encouraging family meetings
- building services in the communities
- addressing psychosocial and practical problems
- effective communication/respect for language
- use of Indigenous workers
- respecting/supporting Indigenous practices
- provision of respite, and
- carer and escort support.

The model encircles these issues with an overarching emphasis on cultural awareness and on the need to use the model to advocate for resources and infrastructure.

The project also concluded that the following would be important to the provision of Indigenous palliative care:

- Providing palliative care services in the community to give people the option of dying at home
- Supporting Indigenous patients and carers
- Improving communication
- Improving funding for staffing, services and resources
- Need for cross cultural education
- Developing strategies for supporting grief and bereavement, and
- Looking at how Darwin Hospice can incorporate cultural aspects.

INVESTIGATORS' CONCLUSIONS

The research developed a model for Indigenous palliative care that was informed by the wisdom of Aboriginal people, their families and the health professional who cares for them. The model outlines the key factors that need to be taken into consideration for effective end-of-life care for Indigenous people in Australia.

The model is designed as a living model that is to be used and interpreted by the individual health and palliative care service. It is intended to be a baseline of information to be applied by service providers to their own unique circumstances.

Implications for theory/policy/practice
The model has been built in such a way as to be adaptable to individual services and organisations. It is therefore fluid rather than prescriptive.

DISSEMINATION OF FINDINGS

There has been significant dissemination of the report through an extensive media (television, radio and newspaper) campaign, networking and a website release. Publications for peer reviewed journals have been submitted and the development of further articles is also planned.

FURTHER RESEARCH

Further collaborations around this area are being discussed.

2. *Development of a 'pop-up palliative care service': a new model to support palliative care delivery in rural and remote Australia*

Lead Chief Investigator:	Prof Kate White
Other Chief Investigators:	Prof Lesley Wilkes
	Prof Patsy Yates
Administering Organisation:	Edith Cowan University
Collaborating Institutions:	Edith Cowan University
	Queensland University of Technology
	Wentworth Area Health Service
Funds granted:	$150 000

RATIONALE

Around a quarter of Australia's population lives in rural communities and a further half a million Australians live in remote regions of the country. Despite a similar incidence of cancer between rural and metropolitan Australia, mortality rates are higher for those who live in rural Australia. Decreasing numbers of rural health practitioners, increased costs associated with delivery in rural and remote Australia and a trend towards centralisation of health care services, negatively affect the health of rural Australia.

The need for health care, including palliative care, in rural and remote Australia remains high. For palliative patients in rural and remote areas accessing specialist resources is made more complicated by economic and geographic barriers and care can be limited by variable community and social supports.

Finding ways in which palliative care and supports can be extended for these patients by identifying and evaluating new approaches to delivering palliative care in rural and in remote Australia would add considerably to the well-being of these communities.

Often palliative needs in rural areas may be intermittent or needs specific. Developing a permanent infrastructure would not be appropriate in these circumstances. Looking at available local resources and gaps would provide a basis for developing a 'pop-up' palliative service model that optimises how local resources and services can be used to respond to a specific palliative need.

ORIGINAL AIMS

To improve the care for palliative care patients and their families in rural and remote communities through the development of a cost-effective model for providing palliative cares services specifically tailored for rural and remote Australia.

Objectives:

1. To develop, implement and test a cost-effective model for providing palliative care services specifically tailored for rural and remote communities.
2. To develop a structured program to assist communities to utilise the model to meet their communities' palliative care needs.

METHOD

The study was conducted in two phases drawing on an action research design.

Phase one involved the development of a Palliative Care Tool Kit (PCTK) to facilitate rural communities in undertaking a critical service review. The PCTK outlined the critical components of a palliative care service and provided a framework for the community to analyse local facilities and resources as well as needs, problems and barriers.

Phase two involved the implementation and evaluation of the new model for providing palliative care in three types of rural communities (large rural centre, rural town and remote community).

KEY FINDINGS

The key findings from the research were:

- The PCTK provided a useful framework to assist rural and remote communities to develop a model for providing palliative care. The services developed utilised existing resources and no additional positions were created.
- The PCTK was identified as being transferable to all members of the health team and community. Two of the three sites identified stronger links being established with the local community, and all three sites increased awareness of resources locally.
- The provision of a co-ordinated approach to palliative care for the local community was identified as being improved in two of the three sites. The third site had not had a palliative care patient at the time of final data collection. The site was positive about the processes they had developed.
- Using a community based approach to managing a health issue, a guiding framework was identified by participants as being transferable to other conditions such as diabetes. They identified the PCTK as a crucial resource that could continue to guide practice, and
- Two sites identified improved co-ordination and continuity of care, among all carers, including relief staff in remote sites.

INVESTIGATORS' CONCLUSIONS

Provision of palliative care in small rural and remote communities is achievable using a community-based approach, which supports communities to develop the model that works for their community.

Implications for theory/policy/practice

The Palliative Care Tool Kit has the potential to be a useful resource for rural communities to develop a sustainable approach to providing palliative care services.

DISSEMINATION OF FINDINGS

To date one publication and three conference presentations have resulted from this study. The study report is being finalised and further publications will result.

FURTHER RESEARCH

Research is ongoing exploring models of providing after hours support in rural communities and support for rural health care providers.

3. The investigation of an innovative telemedicine model to support palliative care delivery in rural and remote Australia

Lead Chief Investigator:	Prof Ian Olver
Other Chief Investigators:	Dr. Mary Brooksbank Dr. Sudar Selva-Nayagam Dr. Ofra Fried Ms Nicola Champion Ms Jane Keeley Ms Kate Morton
Administering Organisation:	University of Adelaide
Collaborating Institutions:	Royal Adelaide Hospital Port Pirie Regional Health Service
Funds granted:	$30 000

RATIONALE

Telemedicine refers to the capacity to deliver medicine at a distance and is most commonly considered to be videoconferencing. Conferences can occur between patients and doctors or allied health workers and videoconferencing has particular application when face to face meetings are impractical due to distance.

Telemedicine has been used successfully for clinical consultations in telepsychiatry. Other applications have been limited due to concerns about the inability to directly examine the patient.

An Integrated Services Digital Network (ISDN) link was established in 1996 between the Royal Adelaide Hospital's Cancer Centre and the Royal Darwin Hospital in the Northern Territory enabling simultaneous voice, video, and text transmission. This link enabled general physicians in Darwin access to the multidisciplinary cancer and palliative care team based at the Royal Adelaide Hospital's Cancer Centre. The review of this link found that the isolated clinicians felt well supported and that communication between the care providers improved. Establishing whether telemedicine, and in particular video phones, offers a mechanism to extend the reach of specialist palliative care provision would be a valuable exercise in identifying ways to support rural and remote communities.

ORIGINAL AIMS

To investigate models where palliative care support may be enhanced by the use of telemedicine, particularly in remote and rural areas.

Objectives:

1. To investigate the use of videophones to improve the communication between rural palliative care nurses (Port Pirie) and more remote general nurses who are caring for their patients.

Changes made to original aims
The aim of the project was unchanged. However the original application involved a broader study with four objectives. Funding for this study deals only with the single objective outlined above.

METHOD
The methodology involved the acquisition and distribution of technology to specialist palliative care nurses in a regional centre and general nurses in more remote areas. The nurses then undertook an evaluation of the use of the videophones including patient satisfaction with the technology.

A descriptive analysis of the evaluation content was undertaken.

KEY FINDINGS
The major points raised by the palliative care nurses are as follows:
- Equipment was easy to use and saved time in service delivery
- Patients too ill to leave home felt less socially isolated
- Palliative nurses had better rapport with the client when they were able to see them rather than just talk to them
- There was some initial reluctance to using the technology, and
- There were some technical issues with images freezing or calls being interrupted.

The remote nurses raised the following points in the evaluations
- The equipment was used sporadically
- While the equipment was easy to use it did need time to set it up when visiting the remote client
- The videophone link enabled an improved assessment opportunity by the palliative nurse being able to see the patient
- There was positive client feedback about the link, and
- There were some technical difficulties related to setting up the equipment.

In general, palliative care nurses, general remote nurses and clients were positive about the use of videophones. The support through the videophones had both a social and clinical component.

INVESTIGATORS' CONCLUSIONS
This research has shown that there are technological solutions to the problem of remoteness of palliative care patients that can be utilised. Telemedicine is part of the solution to having remote patients access specialist palliative expertise. Videophones provide one mechanism to extend specialist palliative outreach although there are some technological and experience barriers that need to be overcome.

The capital equipment cost of the phones is modest and the price of such equipment is rapidly diminishing. This technology does not replace direct contact between patients and professionals, it merely adds to the existing contacts.

Implications for theory/policy/practice
Technological solutions may reduce the problem of remoteness of palliative care patients and improve the support and care of these patients.

DISSEMINATION OF FINDINGS
A conference presentation on this work has been made. A journal article is currently being prepared.

FURTHER RESEARCH
Further research in this area is planned.

4. Assessment of the effectiveness of Australian models of palliative care delivery in four neuro-degenerative disorders

Lead Chief Investigator:	Prof Linda Kristjanson
Other Chief Investigators:	Prof Kate White
	Dr. Judy Wollin
Administering Organisation:	Edith Cowan University
Collaborating Institutions:	Edith Cowan University
	Queensland University of Technology
	University of Melbourne
	Deakin University
Funds granted:	$150 000

RATIONALE

Motor Neurone Disease (MND), Multiple Sclerosis (MS), Huntington's Disease (HD) and Parkinson's Disease (PD) are progressive neurodegenerative diseases that primarily occur in adulthood. The diseases are incurable. MND leads to progressive muscle weakness and wasting, spasticity and speech and swallowing problems. It tends to have a rapid, unremitting and fatal trajectory. The incidence of MND is approximately 1.8 per 100 000 per year. MS causes profound disability associated with fatigue, muscle weakness, and balance and coordination problems during a variable illness trajectory. Approximately 10 000 people are known to have MS in Australia. The incidence of HD is 1 per 10 000. HD is an inherited and fatal brain disorder manifested by worsening involuntary movements, psychiatric difficulties and cognitive changes occurring over a number of years. PD is not a life limiting illness but causes increasing disability over a period of years. The incidence of PD is between 1 and 2 per 1 000 people.

People who suffer from these diseases experience physical and emotional symptoms that require palliation and their families also have special needs. Models of care to address the palliative and supportive needs of these populations have not been systematically examined. There has also been little empirical work on the special needs and concerns of these groups.

Understanding the needs of these four populations would provide useful knowledge to help guide care delivery and resource allocation.

ORIGINAL AIMS

To assess existing models of care delivery to meet the palliative care needs of people living with MND, MS, HD or PD and their families, and recommend improved models.

Objectives:

1. To identify the needs of palliative care services of people in Australia with MND, MS, HD, or PD and of their families
2. To determine the extent to which Australian models of palliative care service delivery meet the needs of patients and their family members in each of these four diagnostic groups and recommend models that will better meet these needs, and

3. To recommend empirically based models of supportive care/palliative care that are more specifically directed towards the needs of these patient groups.

Changes made to original aims
The original aim was changed to include the addition of the need for supportive care as well as palliative care.

METHOD
The study was conducted in two phases.

Phase one used a qualitative exploratory and descriptive design to identify and explore the needs of people with the four described neurodegenerative diseases. Semi structured interviews were conducted with forty patients (ten from each disease group). Interviews were also held with three family groups:
- forty family members of patients early in the disease trajectory
- forty family members of patients in the later disease stage, and
- forty family members of patients who had died in the preceding 3 – 6 months

Phase two involved a large national survey, a mailed out self-administered questionnaire to 1 962 patients and 1 962 carers in the four neurodegenerative disease groups. Information from the literature review and Phase one informed the development of the questionnaire used.

KEY FINDINGS
Seven main themes were identified in the qualitative study. They were:
- Adjusting to the impact of the disease
- Surviving the search for essential information
- Gathering practical support from many sources
- Bolstering the spirit
- Choreographing individual care
- Fearing the future, and
- Getting the message across.

The total number of patients and carers who responded to the questionnaire was 503 and 373 respectively representing a response rate of 26% and 19% respectively.

The national survey showed the financial impact of these disorders with nearly 40% of patients giving up work or retiring early as a result of their illness. The majority of patients were living with their partner or another family member. The median time from diagnosis to survey was seven years. About 40% of patients and carers reported using one to three items of equipment. More than 45% of patients reported needing assistance with domestic tasks such as shopping, transport or maintaining finances. Community rehabilitation, home care and respite were the most commonly used services.

Factor analysis of the survey data showed two main factors relating to carer satisfaction:
- Importance of home support and respite, and
- Important of information and equipment.

For patients the two main factors associated with satisfaction were:

- Importance of a dependable, flexible service, and
- Importance of respite and home care.

Cluster analysis identified two groups of patients (low dependency and high dependency) and two groups of carers (low level of support and high level of support). Number of items of special equipment being used appeared to be a significant indicator for cluster membership for both the patient and the carer groups.

INVESTIGATORS' CONCLUSIONS

This study has provided the first empirical evidence on the needs and service use of these special groups. Models of supportive care will need to recognise the two distinct groups of carers and the factors relating to satisfaction for patients and for carers. These models would need to take into account timing, frequency and type of support provided and the stage of the disease.

The study highlighted the need for improved coordination of care between the various service providers. Better information, more effective communication and the capacity to remain at home as long as possible were all issues for patients and carers.

Implications for theory/policy/practice

The findings provide the basis for recommendations for clinical/ palliative/supportive care for people with neurodegenerative disease.

DISSEMINATION OF FINDINGS

A series of publications have been produced or are in train. Various conference presentations have also been made.

FURTHER RESEARCH

Further research in this field is being planned.

5. Palliative care constituency, utilisation and impact on health care: a Western Australian based epidemiological and sociological study

Chief Investigator (Contact): Dr. Beverley McNamara
Other Chief Investigators: Dr. Lorna Rosenwax
Prof D'Arcy Holman
Ms Ellen Nightingale
Administering Organisation: University of Western Australia
Collaborating Institutions: University of Western Australia
Centre for Health Services Research
Health Department of Western Australia
Palliative Care Australia

Funds granted: $150 000

RATIONALE

There is a lack of population based research on the provision of palliative care services to the dying. To date there is no universally accepted normative benchmark for defining palliative care needs at the population level. While there is evidence to suggest that palliative care is superior to conventional care for the terminally ill patient, there has only been limited work on the use of health services by terminally ill people. This in part reflects the lack of databases that can support such research.

Understanding the patterns of use and relating such patterns to characteristics of various groups provides important information to assist in health care planning, service provision, workforce training and education, and helps assess unmet need in the community.

ORIGINAL AIMS

To evaluate the effectiveness of the existing model of palliative care delivery in the State of Western Australia and to propose a new empirically based model of service delivery.

Objectives:

1. To develop a definition of the service constituency for designated palliative care programs, and implement this definition for the population of Western Australia in 1994-1999
2. To study patterns including time trends of palliative care residential care and acute hospital care delivery during the last 12 months of life within the service constituency, comparing the level of utilisation between different socio-demographic groups (age, gender, social disadvantage, race/ethnicity and metro/rural/remote place of habitation) and causes of death
3. To study the inter-relationships between the different types of services provided to the terminally ill, including rates of transfer between services, place of death and the impact of palliative care on the use of acute hospitals over time
4. To develop a forecasting model to optimise the planning and the delivery of palliative care services in Western Australia, and where appropriate, to generalise this model to other states in Australia, and

5. To evaluate and redefine the service constituency with reference to the forecasting models as well as to the equity and access issues identified above (objectives 2 and 3).

Changes made to original aims
No change was made to the original aims. However the time frame for the population study was changed from 1994-1999 to 2000-2002 to access more up-to-date data and to control the number of International Statistical Classification of Diseases (ICD) data codes used.

METHOD

The study was a longitudinal population-based, retrospective cohort study of 26 882 people who died in Western Australia between 1 July 2000 and 31 December 2002. A secondary analysis was conducted of data from the Silver Chain Nursing Association and two administrative health databases of the Western Australian Data Linkage System - the Mortality Register and the Hospital Morbidity Data System.

An operational definition of a 'designated palliative care program' (or an organised service with specific resources) was established using normative group techniques with four focus groups.

KEY FINDINGS

Objective 1: Definition of service constituency
The definition needed to reflect both non-categorical (symptom needs based) and categorical (condition specific) elements. To operationalise this definition three separate definitions and estimates were used:

- Minimal (Most restricted)
  Death from ten causes – cancer, heart failure, renal failure, liver failure, chronic obstructive pulmonary disease, motor neuron disease/amyotrophic lateral sclerosis, Parkinson's disease, Huntington's Disease, Alzheimer's disease and HIV/AIDS
- Mid-range (Refined comprehensive)
  Person admitted to hospital in the last 12 months for the same condition as recorded on the Death Certificate, and
- Maximal (Comprehensive)
  Deaths from any cause, other than accidental or unexpected causes of death such as poisoning or injury or originating during pregnancy, childbirth, the puerperium or the perinatal period.

The majority of people who comprised the palliative care constituency (minimal, mid-range and maximal definitions) were aged 65 years or older, non-aboriginal, married or widowed and living in the major cities of WA.

Objective 2: Patterns of palliative care, residential care and acute hospital care use
In the last year of life, 42.7% (minimal), 39.3% (mid-range) and 25.3% (maximal) received specialist palliative care. Cancer sufferers were most likely to use palliative services with 91% of non-cancer conditions not using palliative care.

One in four of the palliative care constituency were admitted to hospital for specialist palliative care services in the last year of their life.

Objective 3: Inter-relationships between services
While people who received specialist palliative care services used more total days in hospital care they used less days in general (i.e. non-specialist palliative care services) hospital admissions.
People who received home-based specialist palliative care spent fewer days in total hospital care. They did use more days in specialist palliative care admissions.

Objective 4: Forecasting model
A model was developed using three operational definitions (minimal, mid-range and maximal). This enabled the projection of admissions, bed days and costs for hospital-based and home-based specialist palliative care services if demand increased to 50%, 75%, 90% and 100% of the palliative care constituency.

INVESTIGATORS' CONCLUSIONS
The use of population based data provides an alternative way of assessing impact and resource use associated with palliative care practices. This approach also offers a mechanism to identify and estimate unmet needs.

Many people in Western Australia do not receive specialist palliative care services when they are terminally ill. This is particularly so for people who die of conditions other than cancer; are aged older than 84 years; are Aboriginal; live in remote or geographically isolated areas; or who are socioeconomically disadvantaged. It appears that once referred there is a strong network of specialist palliative services.

The research has also shown that increasing palliative care services has the potential to reduce the demand on other hospital beds. The relative cost implication of this change has yet to be established. Those who do have access to specialist palliative care services are also more likely to die at home. Again the relative cost implications of this outcome has yet to be determined.

Implications for theory/policy/practice
This study breaks new ground by using a population-based empirical analysis to estimate unmet need and identify gaps in the provision of care.

The three tiered approach to calculating palliative care constituency provides the opportunity to project future staffing needs and to inform service provision requirements. The model can also be used to estimate the resource implications of changes in rates of use and relative costs of different specialist care practices.

The data shows that people with non-malignant conditions are not using specialist palliative care services. Understanding the reasons why people are not referred or not catered for under current structures will be important in ensuring that these people get appropriate care.

Similarly, the analysis has identified groups that are not well served by palliative care including the people older than 84 years; Aboriginal people; those who live in geographically remote areas; and socioeconomically disadvantaged groups. These findings support the emphasis given to discussions and studies of the needs in these groups and approaches to providing appropriate care for these groups.

DISSEMINATION OF FINDINGS

A summary report for physicians has been prepared. Other publications are also being produced.

FURTHER RESEARCH

Additional research is being planned including the extension of data linkages to include aged care databases, pharmaceutical benefits information and Medicare material. Further research is also underway to investigate factors that determine met and unmet need for palliative care services in the last year of their lives.

6. Early referral to palliative care: a randomised trial of patients with metastatic cancers and a survival expectation of less than 12 months

Chief Investigator (Contact):	Prof Martin Tattersall
Other Chief Investigators:	Dr. Michael Boyer Dr. Phyllis Butow Dr. Paul Glare Dr. Michael Jackson Prof Jane Hall Dr. Martin Stoeckler
Administering Organisation:	Royal Prince Alfred Hospital
Collaborating Institutions:	Royal Prince Alfred Hospital NHMRC Clinical Trials Centre Centre for Health Economics University of Sydney
Funds granted:	$70 000

RATIONALE

Approximately half of patients referred to medical and radiation oncology departments have metastatic cancer. For most of these patients the goal of treatment is not curative but palliation. The uncertainty of treatment gains must be weighted against the probability of treatment related side-effects when determining whether to undergo a 'trial' of anticancer treatment.

The proportion of terminal cancer patients referred to palliative care services and the timing of such referrals varies widely within and between services. Most referrals to hospital based palliative services are cancer patients. There are however few studies on the role and effect that palliative care services could have on the outcomes for terminal cancer patients.

Understanding the effect of early referral for the patient in terms of symptom management, quality of life and resource use would be of great value in providing the best care for patients with metastatic cancer.

ORIGINAL AIMS

To explore the benefits and costs of consulting with a palliative care physician when patients with incurable metastatic cancer present for treatment to a medical or radiation oncologist.

Objectives:

1. To determine if early referral to palliative care will
   - enhance patient symptom control and satisfaction with care
   - reduce the number and average length of stay of acute hospital admissions, and
   - increase patient choice regarding place of death.

METHOD
The research design involved a randomised control trial of patients with metastatic cancer and a life expectancy of less than twelve months who were referred to participating oncologists. Consenting patients were randomised to standard care or standard care + early referral to a palliative care service. Patients enrolled in the trial were followed from the time of randomisation to the time of death.

Patients in standard care were referred to palliative care as required. Patients in the intervention group were referred to specialist palliative care services at the point of contact with the medical or radiation oncologist.

KEY FINDINGS
The data collection is not yet complete. To date 95 of 114 patients approached have consented. Recruitment will continue until 150 patients have consented.

INVESTIGATORS' CONCLUSIONS
This study is exploring when (or if) in the course of treating patients with incurable cancer, contact with a palliative care service is optimal.

The results of the study will inform future practice and the interactions between cancer treatment centres and palliative care services.

Implications for theory/policy/practice
Awaiting the completion of the study.

DISSEMINATION OF FINDINGS
A conference presentation on the study has already been made. Publications will be prepared when data collection and analysis is complete.

FURTHER RESEARCH
Further research is planned and a grant request has been submitted to the National Institutes of Health in the United States of America.

7. Body composition changes in cardiac cachexia: patho-physiology and quantification

Chief Investigator (Contact):	Dr. David Kaye
Other Chief Investigators:	Dr. John Power
	Dr. Mark Jois
Administering Organisation:	Baker Medical Research Institute
Collaborating Institutions:	Baker Medical Research Institute
	Victorian Institute of Animal Science
	University of Melbourne
Funds granted:	$120 000

RATIONALE

Congestive heart failure (CHF) is a common cardiovascular condition. It accounts for a large proportion of hospital admissions and appears to be an increasingly common disease. The condition is accompanied by high mortality rates. It therefore places a significant burden on health care resources. In common with cancer, CHF is associated with the progressive and refractory loss of lean body mass (or cachexia).

The pathophysiological mechanisms that underlie cachexia are still being studied. The development of an animal model of cachexia would provide the opportunity to describe the development of cachexia from normal to the terminal state and to model the effect of interventions.

One clinical intervention that has been suggested as providing benefits in terms of walk capacity and quality of life for CHF patients is exercise training. Understanding how exercise training impacts upon functional capacity and body composition would support the use of such strategies in the clinical setting.

ORIGINAL AIMS

The aims of this study were twofold:

1. To utilise a unique model of cardiac cachexia to accurately assess the metabolic processes which lead to the development of the cachetic state, and
2. To investigate whether a program of exercise training reverses the features of cardiac cachexia in patients with heart failure.

Objectives:

1. To make a major contribution towards the pathophysiology and treatment of cachexia associated with heart failure. This would be achieved by:
    - A greater understanding of the processes of change from normal to the severely cachetic state
    - A model of cachexia that could be reliably used to test therapeutic interventions, and
    - Evaluating the effects of exercise training in human heart failure.

METHOD
The study comprised two parts – an animal study and an intervention study with CHF patients.

The animal study involved the collection of baseline data for 24 sheep. The animals were randomly allocated to two groups – paced to induce heart failure and non-paced. The control and intervention animals were then matched for daily food intake study at the commencement of the pacing and again after five weeks of pacing.

The exercise training intervention involved 20 patients with stable heart failure. The patients were randomised to a control (usual living) or an 8-week exercise program. Baseline assessments relating to functional, metabolic and cytokine factors were collected. These assessments were repeated at the end of the 8-week training program.

KEY FINDINGS
Initial biochemical analyses of the animal material has begun. The preliminary data suggests that in the animals with cardiac dysfunction there were altered metabolic states with regard to an upward trend for metabolisable energy usage and an altered nitrogen balance. Further analysis will be undertaken on other biochemical variables.

The patient study showed improvements in functional capacity with an improved quality of life and a reduced perception of breathlessness. Further analysis is pending the completion of the analysis of the final body composition data.

INVESTIGATORS' CONCLUSIONS
The study highlighted the effects of heart failure on changes in body composition using both a clinical and experimental animal design. The exercise study provided support for the need for exercise training to be part of care practices for CHF patients.

There is preliminary data that would inform the development of an animal model of cachexia. The preliminary results of the exercise intervention study suggest that an exercise intervention may affect performance scores on various measures.

Implications for theory/policy/practice
An animal model could be developed to describe the mechanisms that underpin the development of cachexia in CHF.

The results of the human study could assist in the development of clinical advice regarding exercise training for CHF patients.

DISSEMINATION OF FINDINGS
Publications are planned for after the completion of data analysis.

FURTHER RESEARCH
Further research in this field is planned.

8. Improve care of dying with chronic heart failure

Chief Investigator (Contact):	A/Prof Patricia Davidson
Other Chief Investigators:	Prof Kathleen Dracup
	A/Prof Peter MacDonald
	Dr. David Gorman
	Prof Jill Cockburn
	Dr. David Rees
	Prof Simon Stewart
Administering Organisation:	University of Western Sydney
Collaborating Institutions:	Southern Eastern Sydney Area Health Service
	University of Western Sydney
	Queen Elizabeth Hospital
	University of California, San Francisco
	University of Newcastle
	RAND Centre to Improve Care of the Dying
Funds granted:	$130 000

RATIONALE

Chronic heart failure (CHF) is a major public health issue for Australia. It is primarily a condition of ageing and is increasing due to an ageing population and success in the treatment of hypertension, acute myocardial infarction and valvular disorders.

Chronic disease with an inevitable terminal outcome creates health management issues for professionals who must balance acute and palliative aspects of care within a context of an unpredictable trajectory of illness. At the moment the evidence base for managing such patients is limited. Understanding how patients with CHF are managed in the health system and the particular concerns of patients, families and health professionals could inform policy, service delivery and patient care.

ORIGINAL AIM

To examine the systems of end-of-life care in the Australian CHF population and to examine the impact of this process upon health professionals, carers and significant others.

Objectives:

1. Identify the policy environment and patterns of end-stage care in an Australian population with chronic heart failure
2. Identify cultural issues and other aspects of diversity to the end-of-life process of CHF
3. Develop and document an evidence based model of care of the dying based on a systematic needs assessment and analysis
4. Identify barriers and facilitators to palliative care in acute care, community, nursing home and hostel settings
5. Evaluate the impact of implementation of best practice guidelines and educational initiatives across institutions, including nursing homes and hostels, and

6. Evaluate measures for measuring quality of care predicting survival and determining patient and family preferences.

METHOD

The research involved two phases.

Phase one involved:

- A medical chart review of patients dying of CHF in six hospital settings (two urban, two rural and two remote)
- Literature review and consultation with patients carers and health professionals, and
- A review of the policy and legislative framework affecting end-of-life care including advance directives

Phase two involved the implementation and evaluation of CHF Palliative Care Best Practice Guidelines against historical baseline data collected in Phase one. Various study endpoints were used such as number of patients dying in different settings, level of medical intervention, use of a systematic palliative care plan, quality of care assessment. These results were supplemented with an economic evaluation and results of questionnaires and focus groups looking at barriers and facilitators to the implementation of the guidelines.

KEY FINDINGS

The model of care for the dying has been completed and incorporated as part of the revised Cardiac Society of Australia and New Zealand/National Heart Foundation Guidelines to be released in March 2005.

A number of key findings were identified by the study:

- There is evidence of clear socio-economic differential in outcomes nationally for heart failure
- There is a need to consider issues related to cultural and ethnic diversity in care delivery
- There is a need for funding and policy support to facilitate palliative care provision in heart failure
- Palliative care issues need to be included in undergraduate and postgraduate curricula
- There is a need to clarify medico-legal considerations in respect to CHF management and advance care directives
- There is a need for a model of clinical supervision in cardiology practice
- There is a need for reliable Australian epidemiological data
- There is a need for education and consumer awareness on the role of Advance Care Directives in heart failure management
- There is a need for the development of administrative and patient management information systems, and
- Cardiology clinicians need education and support surrounding “difficult conversations” involving prognosis and outcome.

INVESTIGATORS' CONCLUSIONS

This research has shown that implementing palliative care principles in CHF is complex and multifaceted. There are implications for policy, professional education, consumer awareness and basic and clinical science. They can be summarised as follows:

- There is a need for education of cardiology clinicians in palliative care and of palliative care clinicians in heart failure management
- Models of care need to be dynamic, flexible and responsive to the individual needs of patients and their families rather than diagnosis
- The issue of access to consumable such as oxygen therapy needs to be examined
- There needs to be information for health professionals and consumers regarding palliative care and heart failure
- Better tools and information and data systems are needed to assist the research agenda in this area
- There is a need for culturally appropriate care
- There needs to be further work on the current funding models. Funding solutions are needed to integrate palliative care principles into the disease trajectory. This would also complement the development of appropriate configurations of service delivery, and
- There is evidence of inferior outcomes in rural and remote Australia.

The active program of dissemination has also promoted the awareness of palliative care nationally and internationally in this field.

Implications for theory/policy/practice

This project has generated extensive material, which will have implications for theory, practice and policy.

The implications can be summarised in four areas

1. Development of expertise and knowledge
2. Issues around funding and models of service delivery
3. Recognition of the importance of the patient including their cultural and carer circumstances, and
4. Development of pharmacological and basic science activities.

The research work has contributed to the revised set of Cardiac Society of Australia and New Zealand National Heart Foundation Guidelines.

DISSEMINATION OF FINDINGS

An extensive program of publication is planned with ten journal articles underway and 24 conference presentations planned. There has also been an active set of affiliated dissemination activities including with key bodies in the cardiovascular field.

FURTHER RESEARCH

Further research activities are planned.

9. Palliative care in aged care facilities for residents with a non-cancer diagnosis

Chief Investigator (Contact): Prof Carol Grbich
Other Chief Investigators: E/Prof Ian Maddocks
Ms Deborah Parker
Administering Organisation: Flinders University
Funds granted: $70 000

RATIONALE
Aged care facilities have an important role in the last months or years of many of Australia's aged population. Many residents in these facilities are in a pre-terminal phase of life suffering from one or more chronic degenerative diseases. This care setting along with hospices has assumed greater responsibility for dying persons. However there is little research on the care of the dying in aged care facilities within Australia and internationally.

Understanding the palliative care needs of residents with a non-cancer diagnosis within aged care facilities would help in assessing the applicability of palliative philosophies and practices developed from cancer services for the aged care setting.

ORIGINAL AIMS
The study aims, with regard to residents of aged care facilities with advanced and terminal illness (non-cancer diagnosis), were to:
1. Understand their distribution and clinical profile in South Australia
2. Identify the nature of their palliative care needs
3. Examine the current contribution of palliative care services for these people, and
4. Evolve strategies that may more adequately address any unmet needs.

Objectives:
1. To define a random sample of aged care facilities and of residents with advanced and terminal illness (non-cancer diagnosis)
2. To describe the unmet needs in this population by
   a. A questionnaire which is directed towards a large representative sample, randomly selected
   b. A more detailed and continuing study over time of a smaller representative sample also randomly selected
3. To describe the availability and utilisation of palliative care services by aged care facilities, and
4. To suggest strategies appropriate to meeting any revealed deficiencies and unmet needs.

METHOD
The project comprised two phases.

Phase one involved a survey of a representative sample of 23 South Australian aged facilities. The survey collected information on the:

- The profile of each facility and palliative policy of each facility
- Details on resident deaths in the previous 12 months, and
- Details on current palliative residents

Phase two involved a prospective study of 69 residents from the same 23 aged care facilities who had a non-cancer diagnosis and for whom palliative care was deemed appropriate. Facility staff identified residents who met the study criteria of non-cancer diagnosis requiring palliative care. Consent was sought from the resident or where applicable next of kin. Data was collected on the resident's physical and psychosocial circumstances and the nature of service and health system supports. Follow up assessments were conducted fortnightly. Following the death of a resident, residential staff provided feedback on their ability to meet the needs of the resident.

KEY FINDINGS

This study shows that unlike clients of specialist palliative care services, residents in aged care facilities have multiple non-cancer diagnoses, cognitive and behavioral problems and are extremely dependent in terms of activities for daily living.

Although these facilities may not have funding arrangements that support the provision of specialist palliative care, they are offering a palliative approach to promote psychological and physical well being for both residents and families.

Seven percent of residents in aged facilities were identified by the Directors of Care as needing a palliative approach, consultation from a specialist palliative care service or a palliative intervention. Approximately half the aged care facilities had at least one resident for whom they had consulted a specialist palliative care service. However few residents have a formal involvement with a palliative care service. Four out of five resident deaths in aged care facilities involved non-cancer diagnoses and 83% of these deaths occurred within the facilities.

The key issues raised during this study fall broadly under four main areas – liaison with palliative care services, education, funding arrangements and policy.

INVESTIGATORS' CONCLUSIONS

The major finding of the study was that residential aged care facilities have accepted and are committed to providing a palliative approach for their residents.

The palliative care needs for residents in aged care facilities can be quite complex given multiple non-cancer morbidities and cognitive and behavioural problems.

Implications for theory/policy/practice

Four strategies were identified to address unmet palliative care needs:

1. An increased liaison between palliative care services and residential aged care facilities
2. Continued education in palliative care appropriate to each staff member's professional development needs and the needs of the organisation

3. Improved Australian Government funding arrangements to assist residential aged care facilities' capacity to meet residents' terminal care needs, and
4. Residential aged care facilities developing a comprehensive palliative care policy as a requirement of the Accreditation Standards

DISSEMINATION OF FINDINGS
Several publications have been produced or are currently being written.

FURTHER RESEARCH
Further research in this field is planned.

10. Renal dialysis abatement: decision-making and social impact of transition to terminal care

Chief Investigator (Contact):	Prof Michael Ashby
Other Chief Investigators:	Prof Allan Kellehear
	Prof Steven Holdsworth
	Ms Denise Brooks
Administering Organisation:	Monash Medical Centre
Funds granted:	$100 000

RATIONALE

Renal dialysis and transplantation have been the subject of research and social review. However the issues around dialysis abatement (either not to initiate or to cease dialysis) have not been well examined. The decision to withhold or withdraw from dialysis is usually very difficult and the process is uneasy for patients, families and carers, and at times the renal unit staff. Dialysis discontinuation is becoming more common as the dialysis population increases and becomes older with more significant co-morbid conditions.

The issues around dialysis abatement would benefit from investigation to assist in mapping out processes to meet patient needs and to develop palliative care pathways where appropriate.

ORIGINAL AIMS

The study aim was to provide:

1. descriptive and systematic data on the social impact of these decisions and processes on patients, families and social networks
2. A re-examination of professional procedures in dealing with patients, particularly concerning disclosure and clinical decision-making and its timing and impact on patients and their families
3. A review of institutional policies with respect to the location and type of care appropriate to such patients, and
4. Demographic and clinical data concerning patients who cease or elect not to start dialysis, and therefore die of renal failure.

METHOD

This was a qualitative study using Grounded Theory to explore phenomena from the participant's everyday life and to identify relevant themes.

There were three groups of participants

- Patients who had discontinued renal dialysis therapy
- Patients who decided to forego or withhold dialysis, and
- Spouses of these patients.

During the early stages, the research team agreed to target patients first and foremost and their families/carers only where appropriate and not exclusively.

Where possible two interviews were held one around the time of the decision-making to withhold or withdraw and the other two to three weeks later.

KEY FINDINGS

The patient experience is crucial to the decision-making around withdrawing or withholding renal dialysis. This study suggests that for many patients the burdens of treatment may outweigh the benefits.

The following qualitative themes arose from the analysis for each of the three groups.

Patients withdrawing from dialysis:

- A profound sense of suffering
- Life on dialysis was intolerable and problematic
- Not to be a burden
- A philosophical acceptance
- The hope for a quick and pain-free death, and
- A sense of abandonment and uncertainty.

Patients withholding from dialysis:

- Dialysis as disruptive to family and social life
- Other comorbidities and medical uncertainty
- Dying as a natural course
- Inaccurate prognoses
- Lay theories about success in surviving longer than prognosis
- Importance of family acceptance of the decision, and
- Living on borrowed time.

Spouses of patients:

- Family supportive of patient's decision
- Importance of the manner of disclosure
- Preparation of diet and medications, and
- Quality time with the patient.

The interview data suggests that withdrawing from treatment may be more difficult and more likely to be made by the patient alone than the decision to withhold from treatment. Medical uncertainty was a recurrent theme for the participants and indicates that an evidence base to guide practice is still developing.

A series of suggestions were made regarding the issues raised by patients and spouses in the study.

INVESTIGATORS' CONCLUSIONS

This research shows that potential improvements in practice require a strategy that will fully integrate the advances of palliative care into the processes of renal dialysis abatement. Collaborative management earlier in the illness trajectory may offer opportunities to support patients and enable gentler transitions from dialysis to palliative care.

The uncertainties and complexities faced by renal patients during end-of-life care indicate that further research is needed to develop an evidence base to support care practices.

Implications for theory/policy/practice
The research highlights the need for collaborative management of patients by nephrology and palliative care earlier in the illness to enable support for decision-making and appropriate transitions in care planning. This needs to be supported by policy changes to renal management of end-of-life care.

Joint management between palliative care services and renal services has the potential to promote well being and chronic pain management during dialysis as well as at the end-stage.

There is the relative absence of broadly based community and professional discussion of the relationship between renal failure and death.

There is a need for greater openness in discussions of death and dying not only in the clinical setting but also in the community.

DISSEMINATION OF FINDINGS

Journal articles on the study are being prepared.

FURTHER RESEARCH

Further research is planned.

11. Understanding factors contributing to nausea: clinical and patient perspectives

Chief Investigator (Contact):	Prof Patsy Yates
Other Chief Investigators:	Dr. Alexandra Clarion Dr. Geoff Mitchell Dr. Peter Hudson Dr. Grant Cameron
Administering Organisation:	Queensland University of Technology
Collaborating Institutions:	Queensland University of Technology University of Melbourne Royal Brisbane and Women's Hospital Prince Charles Hospital St Luke's Nursing Service Eastern Palliative Care Caritas Christi Hospice
Funds granted:	$100 000

RATIONALE

Nausea is a complex multicausal condition that significantly affects the quality of life of patients with end stage cancer. Nausea is an important clinical problem. Due to the multiple potential causes of nausea at the end stages of life, it can be difficult to assess and manage effectively.

There is some literature regarding frameworks for assessing the multitude of factors that may contribute to nausea. However, these frameworks have not been validated. There is also limited evidence regarding systematic approaches to the assessment and management of nausea.

Identifying the specific factors affecting nausea will contribute to more effective assessment and enable a more targeted approach to the management of this symptom.

ORIGINAL AIMS

To develop and validate indicators that can be used to more effectively identify nausea and its contributing factors in patients with advanced cancer admitted to inpatient and community palliative care settings.

Objectives:

1. Undertake a systematic review of the literature to identify clinical and psychosocial factors contributing to nausea in patients with advanced cancer
2. Describe patterns of prevalence, severity and distress associated with nausea in patients with advanced cancer admitted to a palliative service
3. To identify clinical and psychosocial factors that are associated with advanced cancer patients' reports of nausea, and
4. To examine the relationship between clinicians' and advanced cancer patients' ratings of nausea.

METHOD

The research is being undertaken in two phases.

Phase one: Development of a clinical assessment process
This phase involves two components, a systematic review of the literature and a consultation process using qualitative interviews with clinicians and patients to refine the clinical assessment process.

Phase two: Validating the clinical assessment process and factors contributing to nausea
Structured interviews with patients at participating institutions in Queensland and Victoria will be conducted to evaluate their experience of nausea and related symptoms. For each patient staff will be asked to complete a tool involving clinical and psychosocial factors contributing to nausea and to provide a rating of the patient's nausea.

INTERIM FINDINGS

This project is still continuing and key findings are not yet available. However the investigators have provided the following interim comments:

- The systematic review with regard to clinical and psychosocial factors that may contribute to nausea in patients with advanced cancer and the efficacy of methods for assessing nausea in patients with advanced cancer has been completed
- Seventeen patients were interviewed to describe the subjective aspects of nausea. Themes identified were used to develop the clinical assessment tool
- Interim analysis of data from 3 157 patients has been undertaken to identify nausea prevalence rates. An estimated 20% of patients (either by self-report or proxy rating by clinician) had suffered nausea in the past week, and
- The validation study is continuing. To date 102 patients have been recruited. A further 28 are needed to provide an appropriate sample size for analysis.

INVESTIGATORS' CONCLUSIONS

Conclusions will be reported at the end of the study.

Implications for theory/policy/practice

Implications will be reported at the end of the study.

DISSEMINATION OF FINDINGS

A series of publications based on this study are planned.

FURTHER RESEARCH

This will be determined at the end of the study.

12. Objective assessment (based on whole body bio-impedance) of the trajectory of the course of illness for end of life non-cancer related diseases: biological, social and environmental determinants

Chief Investigator (Contact):	Prof Neil Piller
Other Chief Investigators:	E. Prof Ian Maddocks Dr. Roger Hunt Mr. Adrian Esterman
Administering Organisation:	Flinders University
Collaborating Institutions:	Flinders University North Western Adelaide Health Services (Lyell McEwin Health Service and Queen Elizabeth Hospital) Repatriation General Hospital
Funds granted:	$120 000

RATIONALE

There are increasing demands on palliative care services to contribute to the terminal care needs of people with advanced diseases other than cancer. Whereas the terminal trajectory or decline of cancer is relatively consistent and documented, the last phases of disorders such as congestive heart failure, liver disease, chronic obstructive pulmonary disease or failed organ transplant are difficult to track and predict. This creates a dilemma for specialist palliative care services in determining admission priorities to support services and specialist facilities.

Patients with non-cancer diagnoses may not be included in specialist palliative services because discomforts are not as great as in cancer and because the prognosis is uncertain.

Regardless of the cause of an end-of-life disease or disorder, it will usually involve multi organ system failure and significant changes in body composition. Recent advances have meant that it is possible to accurately track changes in several components of body composition with great accuracy using the technique of bio-impedance. Changes in lean body mass may be used as an indicator of the progression of a disease to its terminal phase and bio-impedance provides a mechanism to assess these changes more accurately than bedside observation.

The study will also offer the opportunity to correlate changes in bio-impedance measurements with social or environmental changes providing insights into the effects of these influences on disease progression.

ORIGINAL AIMS

To assess change and the rate of change in whole body mass and segmental body parameters of extracellular fluids, intracellular fluids, protein mass, muscle mass (and type), bone mass, lean body mass and a series of associated physical measures.

Objectives:

- To measure differences in the rate of change of three groups of non-cancer disease patients through the last phase of life
- To compare measurements at the entry point to palliative care with those taken near to the end of life for these three groups
- To correlate the findings with indices or scales representing biological, social or environmental determinants, and
- To compare outcomes with a cancer related palliative care group as a baseline.

METHOD

The proposed study is a descriptive study involving a sample of at least 20 and up to 50 patients in each of three major groups (Chronic Obstructive Airways Disease (COAD), Motor Neurone Disease (MND) and cardiac failure). Comparisons will be made with a cancer-related group. Each subject would ideally have four bio-impedance measurements made over a period of a minimum of 8 weeks and be followed for the duration of their time following recruitment or referral to the palliative care service and on to as close as is feasible to the time of death. Clinical assessments of physical and emotional function and of major symptoms will be made using a range of cross group tests (Geriatric Depression Scale, Edmonton Symptom Assessment Scale, Mini Mental) in patients and their partners/carers.

INTERIM FINDINGS

This project is still continuing and key findings are not yet available. However the following interim comments have been provided:

- An ongoing finding of the study has been the level of depression evident in all patients interviewed. This depression appears to revolve around two time frames – immediate concern for their clinical status and/or distress about long standing unresolved life grievances. Importantly, the degree of depression in the patient correlates with the degree of depression the partner/carer observes in the patient and relationships are appearing between the Edmonton Symptom Assessment Scale and the Geriatric Depression Scale
- The issues around addressing depression are made more complicated by the question of when or how palliative care approaches are introduced for those patients with a chronic or progressive illness who are still being managed in a curative environment
- A superficial interrogation of the data shows significant trends in the major variables, the progression through illness and the arrival at the end point of life
- Of particular importance is the examination of the interrelationships between the key psychological and physical measures and the specialists' estimate of survival and a determination of which factors currently influence that decision
- In cardiac and respiratory groups introducing palliative care as management may appear premature at times
- At present it is difficult to answer the question "where does the trajectory start?" The in-depth analysis of the full data set may provide more information, and
- Demands of different ethics committees often make the utilisation of uniform procedures/processes across the institutions difficult.

INVESTIGATORS' CONCLUSIONS

The project, as expected, is a very difficult one. Trends are being found and it is likely that the data will inform the major aims of the study.

Implications for theory/policy/practice

The interim analysis shows that depression is a serious and significantly unattended issue. Depression revolves around two time frames – the patient's immediate concern about their clinical status and/or distress about long-standing unresolved life grievances.

For patients who are chronically ill with a severity of disease progression that deems them palliative or pre-palliative, preliminary psychological assessment may be useful to determine if more comprehensive psychological supports are needed.

DISSEMINATION OF FINDINGS

Interim findings have been discussed and presented at various local meetings. Further publications are planned following completion of data collection and analysis.

FURTHER RESEARCH

This will be determined at the end of the study.

13. Improving the management of nausea in advanced cancer: pragmatic tools for the assessment and treatment of nausea in clinical practice

Chief Investigator (Contact):	Dr. Paul Glare
Other Chief Investigators:	Dr. Martin Stoeckler Prof Linda Kristjanson Prof Martin Tattersall
Administering Organisation:	Royal Prince Alfred Hospital
Collaborating Institutions:	Royal Prince Alfred Hospital Repatriation General Hospital, NSW Edith Cowan University
Funds granted:	$100 000

RATIONALE

Nausea and vomiting are common experiences of patients with advanced cancer, independent of exposure to chemotherapy or radiotherapy. Up to 60% of patients with advanced cancer are affected by nausea and around 30% by vomiting. These two symptoms have a significant effect on the patient's quality of life.

Over the past two decades specialists in the field of palliative care have developed strategies for assessing and treating nausea in advanced cancer patients that appear to be safe and effective.

The management of pain in palliative care is based around a rigorous assessment involving a patient's history, physical examination and investigations as to the cause of pain. Correct identification of the cause assists in determining the most effective therapy. This approach could be applied to other symptoms such as nausea.

By developing practical evidence based tools such as guidelines, algorithms or pathways for use by non-specialist clinicians the assessment and treatment of nausea in patients with advanced cancer could be supported.

ORIGINAL AIMS

To improve the management of chronic nausea in people with advanced cancer by developing pragmatic evidence based tools and training clinicians to use them.

Objectives:

1. To carry out a systematic review of the literature on nausea in advanced cancer
2. To develop, pilot and validate an assessment tool to determine the mechanisms and severity of nausea in advanced cancer based on the findings of the review. This will include a comprehensive set of items for clinical research and a pragmatic subset of items for routine clinical practice
3. To develop, pilot and validate a pragmatic treatment tool to guide pharmacotherapy for nausea in advanced cancer based on the systematic review
4. To develop an educational intervention based on the assessment and treatment tools to train non-specialist clinicians who currently provide end of life care, such

as General Practitioners, Junior Medical Officers and Registered Nurses, to better manage nausea in advanced cancer

5. To develop and pilot a randomised trial to test the package (educational intervention and tool), and
6. To prepare and submit grant applications for a definitive, national, multicentre randomised trial of this package.

METHOD

The study methodology included the following stages:

1. Systematic review of all randomised and quasi randomised controlled study for nausea in advanced cancer
2. Development of an assessment tool to determine the mechanisms of nausea in advanced cancer and to measure the severity and distress associated with this nausea
3. Development and validation of tools to guide pharmacological and other therapies for nausea based on the findings of the systematic review, and
4. A randomised trial to test the educational intervention and assessment and pharmacological tools with non-specialist clinicians in selected institutions in Sydney and Perth.

INTERIM FINDINGS

This project is still continuing and key findings are not yet available. However the investigators have provided the following interim comments:

- The systematic review on nausea in advanced cancer has been completed and published. The review showed that there are gaps in the evidence base for managing nausea in advanced cancer
- There were unanticipated pressures in developing the clinical guidelines due to lack of knowledge about the processes for guideline accreditation and limited experience with guideline development
- Capacity building of the palliative care workforce with regard to Evidence Based Medicine skills is needed
- While the nausea guideline implementation and evaluation is underway, the difficulty in leakage of the tool between the intervention and control groups made a Randomised Controlled Trial study design impractical, and
- There are indications that nausea and vomiting may not be common in the general hospital population and may be over-represented in palliative care settings.

INVESTIGATORS' CONCLUSIONS

These will be reported at the end of the study.

Implications for theory/policy/practice

These will be reported at the end of the study.

DISSEMINATION OF FINDINGS
The systematic review has been published. Further publications are planned.

FURTHER RESEARCH
This will be determined at the end of the study.

Section 3: Implications for the field

Value of the National Palliative Care Research Program

The National Palliative Care Research Program has provided a series of benefits that go beyond the value of the individual research studies. The program itself has provided the opportunity to not merely add to the evidence base for palliative care but has profiled that evidence and research base for the broader research community in the health sector. It has demonstrated that it is possible to carry out complex sensitive research with a population that traditionally has been regarded as vulnerable. The ethical and methodological issues associated with research on a palliative population can be successfully addressed.

The Research Program has also contributed to the development of the palliative research in a number of ways, by:

- Building a research culture that will support the evidence base to drive clinical and service delivery
- Providing clinicians, educators and researchers in the palliative field with the opportunity to participate in national level projects providing experience and success that will feedback into the palliative and the research fields
- Supporting cross collaboration between disciplines to build awareness and understanding of the overlaps between specialisations and the specific contributions of the individual specialisations to enhanced patient care and outcomes
- Establishing new collaborations both within the palliative care community and between clinical specialty areas that will create a more robust research community and one that will grow in stature and recognition
- Increasing the number of clinicians with research experience providing a more substantial and mature base for future work and future collaborations as well as providing a significant resource for the review of grant applications and research work, and
- Supporting the use of various methodological approaches to demonstrate not only the breadth but also the complexity of the field of study.

The Research Program has also importantly afforded palliative care recognition as a legitimate area of research interest. This must be translated into a continued participation by palliative researchers in grant based research individually, in palliative collaborations and in collaborations with other specialisations on topics of importance to the care of patients at the end of life. It needs also to be translated into the research infrastructure to recognise palliative care as an area of ongoing enquiry within the national research framework including nomination as a specific field for NHMRC grants application purposes.

Overview of findings for practice and service delivery

The diversity of the studies funded shows that end of life care is multifaceted and complex. The questions being addressed are based in day to day practice and therefore have a direct clinical and practice relevance. The Research Program has also highlighted that there are gaps in knowledge that affect both the clinical care and service delivery for individual palliative patients and specific palliative groups and

subpopulations. Although the results of specific projects are covered in the individual summaries there are common themes that run through the research and the findings from the studies and these themes will be noted here.

Each of the studies relating to non-cancer groups highlights the difficulties in determining when a complex illness moves to a phase where palliative and supportive care is the predominant clincial approach. These results also raise important questions about the role that palliative care should take in these circumstances and how and by whom palliative care should be provided. The studies on CHF, renal end failure and metastatic cancer also highlighted the importance of palliative aspects of care for the patient. This work has important ramifications with regard to the interactions between palliative teams and specialists from other disciplines.

Similarly, the role of specialist palliative care teams and services with respect to care providers in community, regional and aged care facilities was highlighted. The question of how the knowledge and expertise of specialist providers can be accessed by or shared with those providing care outside of specialist settings was a recurrent theme in the findings and recommendations.

Many of the studies examined how knowledge could be translated into practice. This is an area of great importance as research that exists without transfer to those providing care delivers little benefit to the ultimate consumer of services. However, it is also important that where changes to practice are recommended such recommendations are based on the review and evaluation of the field of evidence rather than any individual study. Many studies addressed this issue, in part, by a formal review of the state of the literature and existing evidence.

A number of studies have increased evidence based practice through the development of guidelines or care pathways to assist in the direct provision of care. Others have made a major contribution in terms of the transfer of the knowledge from research to the clinical settings through the development of collaborations with professional bodies, peak organisations and policy and advisory groups. This relationship between the research and policy/clinical groups enhances the potential uptake by the clincial community.

Many studies have reflected on the individual for whom death is the outcome. The importance of understanding the patient's needs and views has been highlighted. This has been reinforced in findings and recommendations with regard to the need for palliative education, for community discussion about death and dying and for balance between palliative and acute care in specialty fields.

The total Research Program also demonstrated the diverse methodological approaches used to investigate issues in palliative care. The range of study methods used highlighted the rich contribution made by the multidisciplinary collaborations and by the diverse academic traditions that support palliative care research. This diversity enables issues to be illuminated or framed in different ways moving from individual narrative to whole of population analysis.

The Research Program has also demonstrated that the palliative care community is well prepared to undertake complex and significant research in a timely and cost effective way. All projects were completed or are working within negotiated timeframes. There is

also a substantial publication and presentation output associated with the Research Program. (See Appendix B)

Development of the research community

Building the research capacity of palliative care was one objective of the National Palliative Care Research Program. The various projects provided some researchers with their first experiences as investigators allowing them to learn the processes associated with guiding major research work. Thirty-six research and/or technical staff were involved with the projects developing a skill base in project and research management, literature searching and reviewing, ethics, interviewing, data collection, data analysis, report preparation and publication. Five postgraduate staff were also employed on the various projects providing valuable experience for their career development.

Of the ten projects that have reported all have indicated that they have or are publishing findings related to the projects. All ten projects intend to continue research in this field. Many of the collaborations have indicated that they will seek further NHMRC funding or funding from other agencies including international sources of funding. Others have already acquired additional funding.

Implications for the future

The National Palliative Care Research Program provided an important first step in building the evidence base for palliative care and in building the research culture and capacity to develop and enhance clincial care and service delivery in palliative care. While this work is significant, it is important to continue with not only new studies but also with studies that replicate and validate existing results to ensure that the evidence base is solid. It is also important to build logically on the next steps of these areas of research to optimise future research advances based on these results.

The research effort that is currently underway has established links into other specialty areas and these relationships should be continued to inform the development of collaborative and integrated research on palliative care in different settings. By utilising the skills and knowledge of different clinical specialties and disciplines, a more comprehensive evidence base can be built. This will be reflected in broader research topics utilising relevant methodologies to investigate complex clinical and public health questions.

As knowledge accumulates from the research programs, it is important to ensure that this knowledge is translated into practice. This may occur by conference presentations and publications and through efforts to guide service development and inform clinical judgement and health policy. The promotion of research efforts and results is also critical to ensure that the clinical and consumer communities affected by palliative care value the research that underpins the provision of care.

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Appendix A: Membership of the Palliative Care Research Working Committee and the Palliative Care Research Committee

Palliative Care Research Working Committee

Professor Mohamed Khadra
Professor David Currow
Mr. John Delaney
Associate Professor Sanchia Aranda
Ms Kim Boyer
Mrs Rita Evans
Mr. David Clarkson
Dr Jack Best

Palliative Care Research Committee

Ms Kim Boyer
Mr. Clive Deverall
Professor Linda Kristjanson
Ms Heather D'Antoine
Professor Ray Lowenthal
Dr. Heather Buchan
Professor David Currow
Dr. Martin Stockler
Professor Sanchia Aranda
Mrs Rita Evans
Mr. David Clarkson

Appendix B: Summary of Publications and Presentations Relevant to the National Palliative Care Palliative Research Program

Conference Presentations

Davidson PM, Cockburn J, Webster JK, Rees DM, Paull G, Stewart S Patients with chronic heart failure rate psychosocial and existential needs higher than physical needs when recently discharged from hospital European Society of Cardiology, Vienna, September 2003

Davidson PM, Cockburn J, Webster JK, Rees DM, Paull G Patients with chronic heart failure rate psychosocial and existential needs higher than physical needs when recently discharged from hospital 7th Australian Palliative Care Conference, September 2003, Adelaide,

Davidson PM, Paull G, Introna K, Cockburn J, Davis JM, Rees DM, Gorman D, Mangan L, Lafferty M, Dracup K Integrated collaborative palliative care in heart failure. The St. George Heart Failure Experience 1999-2002 7th Australian Palliative Care Conference September 2003, Adelaide

Davidson PM et al Improving care of the dying with chronic heart failure (PROCARE): Study methodology and progress to date (Invited report) 7th Australian Palliative Care Conference September 2003, Adelaide

Davidson PM, Paull G, Introna K, Cockburn J, Davis JM, Rees DM, Gorman D, Mangan L, Lafferty M, Dracup K Integrated collaborative palliative care in heart failure. The St. George Heart Failure Experience 1999-2002 Heart Failure Society of America 7th Annual Scientific Meeting Las Vegas 2003

Davidson PM, Cockburn J, Webster JK, Rees DM, Paull G, Patients with chronic heart failure rate psychosocial and existential needs higher than physical needs when recently discharged from hospital Heart Failure Society of America 7th Annual Scientific Meeting Las Vegas

Davidson PM, Cockburn J, Webster JK, Rees DM, Paull G What are the needs of people with heart failure? Presented at the Biennial Health Psychology Conference, Department of Medical Psychology, Westmead Hospital, Sydney, 2004

McGrath P, Watson J, Derschow B, Murphy S, Rayner R The Development of innovative models for indigenous palliative care in the Northern Territory 7th Australian Palliative Care Conference 2003, Adelaide

McGrath P, Watson J, Derschow B, Murphy S, Rayner R, Holewa H, Patton M, Olgivie K Indigenous Palliative Care Service Delivery - A living model Annual Queensland Health and Medical Scientific Meeting 2004

Olver IN, Brooksbank M, Champion N, Keeley J, Healey T Exploring telemedicine to extend palliative care outreach in remote communities American Society of Clinical Oncology Annual Meeting 2003

Tattersall M et al Clinical Oncological Society of Australia Annual Scientific Meeting 2004

Publications

Close G, Davidson PM, Fung SC, Dennis AR, Halcomb E, Newton P, Kavoor P A mandate to consider socio-economic factors: patterns of heart failure hospitalization and disease burden in metropolitan Sydney Australia (Submitted)

Davidson PM, Paull G, Cockburn J, Davis JM, Rees DM, Gorman D, Mangan L, Lafferty M, Dracup K Integrated Collaborative palliative care in heart failure: the St. George Heart Failure Service experience 1999-2002 *Journal of Cardiovascular Nursing 2004* 19(1): 68-75

Davidson PM Cockburn J What do patients really need? – The prevalence of unmet needs following a recent admission to hospital with heart failure *Journal of Cardiovascular Nursing In* press

Davidson PM, Introna K, Cockburn J, Daly J, Dunford M, Dracup K Synergising acute care and palliative care philosophies to optimise nursing care in cardiorespiratory disease Australian *Critical Care* 2002 15(2): 64-69

Davidson PM, Introna K, Daly J, Paull G, Jarvis R, Fox J, Wilds T, Cockburn J, Dracup K Exploration of cardiorespiratory nurses perceptions of palliative care in non-malignant disease: a strategy to inform clinical practice development *American Journal of Critical Care* 2003 12: 47 –53

Davidson PM, Stewart S, MacDonald PS, Dracup K Patterns of death in Australia from heart failure: implications for policy and practice. (Submitted)

Davidson PM, MacDonald PS, Tonkin A, Stewart S, Paull G, Davis JM, Introna K, Dracup K On behalf of the PROCARE Investigators Dying with chronic heart failure: a review of the ethical and legal implications in Australia (Submitted)

Davidson PM, Paull G, Rees DR, Daly J, Cockburn J Narrative analysis of documentation: documentation of the home based heart failure nurse role American *Journal of Critical Care* (In press)

Davidson PM, Moser DK, Stewart S, Phillips J, Dracup K End of life discussions for people with heart disease: a need to consider cultural diversity (Submitted)

Dawson S, Kristjanson LJ, Toye CM, Flettt P Life with Huntington's Disease: Needs for supportive care *Nursing and Health Sciences* 2004 6: 123-130

Dunford T, Davidson PM, Daly J, Dracup K Advanced care directives: a review of the medicolegal context (Submitted)

Glare P, Pereira G, Kristjanson LJ, Stoeckler M, Tattersall M Systematic review of the efficacy of antiemetics in the treatment of nausea in patients with far advanced cancer Supportive *Care in Cancer* 2004 12(6): 432 – 440

Grbich C, Maddocks I, Parker D, Piller N, Brown M, Willis E Documenting end of life decisions in residential aged care facilities in South Australia *Australian and New Zealand Journal of Public Health* 2005 29(1): 85 – 90

Grbich C, Maddocks I, Parker D, Piller N, Brown M Willis E Palliative care in aged care facilities in South Australia for residents with non-cancer diagnosis: the results of a survey *Australasian Journal on Ageing* (In press)

Grbich C, Maddocks I, Parker D, Piller N, Brown M, Willis E, Hoffmeyer A Inclusion criteria for people with a non-cancer diagnosis who are palliative in an aged care facility *Palliative and Supportive Care* (In press)

Hudson P, Toye C, Kristjanson L Palliative and supportive needs of people with Parkinson's Disease and their family caregivers (Submitted)

Kristjanson LJ, Toye C, Dawson S New dimensions in palliative care: A palliative approach to neurodegenerative disorders and the final illnesses of elders *Medical Journal of Australia* 2003 179(6): S42 – S44

Kristjanson LJ, Nightingale E, Dawson S, Harris R Supportive and palliative care for individuals with MND and their carers (Submitted)

McGrath P, Watson J, Derschow B, Murphy S, Rayner R *Indigenous Palliative Care – A living model Uniprint* NT 2004

McGrath P, Watson J, Derschow B, Murphy S, Rayner R *Indigenous Palliative Care – A living model, Companion Booklet* Uniprint, NT, 2004

McNamara B, Rosenwax L, D'Arcy Holman C, Nightingale E *Who receives palliative care in Western Australia and who misses out* Summary University of Western Australia 2004

McNamara B, Rosenwax L, D'Arcy Holman C, Nightingale E Who *receives specialist palliative care in Western Australia and who misses out* University of Western Australia 2004

Parker D, Grbich C, Brown M, Maddocks I, Willis E, Roe P A palliative approach or specialist palliative care *Journal of Palliative Care* (In press)

Wollin J, Yates P, Kristjanson LJ The supportive needs of people with multiple sclerosis (Submitted)