



Australian Government
Department of Health and Ageing

EVIDENCED BASED CLINICAL PRACTICE GUIDELINES IN PALLIATIVE CARE FOR THE MULTI-DISCIPLINARY TEAM

THE NATIONAL
PALLIATIVE CARE
PROGRAM



October 2003

CONTENTS:

Actions arising out of a Workshop of key stakeholders, held on 29 May 2003 to explore the feasibility, justification and potential for evidenced based clinical practice guidelines in palliative care for the multi-disciplinary team..... Page 3

Report from the Workshop of key stakeholders – 29 May 2003.....Page 9

Background Paper prepared for the Workshop of key stakeholders – 29 May 2003.....Page 14

Multi-disciplinary Statement of Principles and Core Values.....Page 23

ACTIONS ARISING OUT OF A WORKSHOP OF KEY STAKEHOLDERS, HELD ON 29 MAY 2003 TO EXPLORE THE FEASIBILITY, JUSTIFICATION AND POTENTIAL FOR EVIDENCED BASED CLINICAL PRACTICE GUIDELINES IN PALLIATIVE CARE FOR THE MULTI-DISCIPLINARY TEAM

1. Purpose

This Section outlines actions arising from a Workshop of key stakeholders who came together on 29 May 2003 to explore the feasibility, justification and potential for evidenced based clinical practice guidelines in palliative care. It has been prepared by the Australian Department of Health and Ageing in consultation with the Palliative Care Intergovernmental Forum (PCIF).

2. National Palliative Care Strategy and Program

The Australian Health Ministers' Advisory Council (AHMAC) endorsed the *National Palliative Care Strategy* in October 2000. The Strategy represents the commitment of the Australian Government, and the State and Territory governments, in conjunction with other key stakeholders, to the development and implementation of palliative care policies, strategies and services that are consistent across Australia, and to the delivery of quality palliative care that is accessible to all people who are dying.

To support the National Strategy, the Australian Government has made available a total of \$201.2 million throughout the five years of the Australian Health Care Agreements (2003-2008) for palliative care. Of this, \$188 million is broadly allocated on a per capita basis to States and Territories for continued service provision, and \$13.2 million for the Australian Government to implement a national program of initiatives.

In addition to this funding, the Australian Government also committed \$55 million over four years in the 2002 Federal budget for national activities to support improvements in the standard of palliative care offered in local communities.

Funding for national activities, known as the National Palliative Care Program has provided the opportunity to improve the quality of palliative care through the provision and co-ordination of a national program of initiatives. This national program is being implemented across the following six broad priority areas:

1. Provision of an expanded range of medications for palliative care in the community
2. Assistance for families and increased support to other care networks
3. Education, training and support for the primary care workforce
4. Increasing the range and reach of palliative care services
5. Capacity building in the palliative care research community
6. Performance information development.

Details of the specific initiatives being progressed within each of these priority areas are available on the National Palliative Care Program website at www.palliativecare.gov.au.

3. Policy Context

The National Palliative Care Strategy recognises that the needs of people who are dying and their families span the physical, psychological, emotional and spiritual domains, and that palliative care therefore ideally involves a team approach with a blending and coordination of skills and disciplines (page 6). In addition, Strategy 2.4.2 under Objective 2.4 – Service Development, identifies the need to support the development and implementation of best-practice guidelines and clinical pathways in palliative care (page 19).

Increasing the range and reach of palliative care services, and education, training and support for the primary care workforce are also encompassed within the six broad priority areas identified above to implement the 2002 Budget initiative.

4. Palliative Care Intergovernmental Forum

The Palliative Care Intergovernmental Forum (PCIF) includes representatives from State and Territory Governments who work in the area of palliative care as well as the Australian Department of Health and Ageing.

The PCIF is the national forum that oversees the implementation of the *National Palliative Care Strategy*. Through this forum state and territory governments provide advice to the Department of Health and Ageing on national initiatives funded under the National Palliative Care Program. Final decision making on these national initiatives resides with the Department.

State and Territory members of the PCIF also work within their jurisdictions to support quality service delivery in palliative care within the policy framework of the *National Palliative Care Strategy*.

The Terms of Reference for the PCIF are:

1. Work together to implement an agreed (and if necessary revise) National Strategy for Palliative Care 1998-2003.
2. Work together to reach agreement on strategies to develop, refine, implement and report on appropriate high level palliative care performance indicators (including indicators of access to and quality of palliative care services), under the Australian Health Care Agreements (AHCAs).
3. Provide input, where necessary, into palliative care performance indicator work and data management and reporting issues, undertaken by key stakeholders.
4. Consider strategic policy issues and provide input on strategies and alliances, that will strengthen the care of the dying across all sectors of the health system, including any associated sector reforms in health, education/training, media, community social support and other areas.
5. Share key information and innovative policies for health care of the dying;
6. Develop collaborative networks and assist in identifying research priorities; and

7. Disseminate information that will improve services for the dying, assist the multi-disciplinary groups who provide this care, and educate the Australian community about care of the dying.

5. Workshop on Development of Evidenced Based Multi-disciplinary Guidelines for the Provision of Palliative Care

5.1 Overview

A project to enhance the quality and effectiveness of palliative care service delivery and to promote and support partnerships in the provision of care through the development of evidenced based clinical practice guidelines in palliative care for the multi-disciplinary team was proposed for consideration for funding under the National Palliative Care Program (NPCP).

In considering this proposal the department sought to consult with key experts on a number of related areas, and hosted a Workshop to:

- Define the need for multi-disciplinary guidelines;
- Define the target audience;
- Identify barriers to the development of multi-disciplinary guidelines; and
- Identify strategies to overcome identified barriers

5.2 Workshop Membership:

The Workshop was facilitated by Associate Professor Kate White, School of Nursing and Public Health, Edith Cowan University and attended by palliative care experts, a Palliative Care Australia representative, clinicians with expertise in guideline development and representatives from the Department of Health and Ageing. A number of key disciplines were represented, including psychiatry; psychology, general practice; social work; occupational therapy; medical; nursing; spiritual adviser; and a community representative.

Several factors were identified that would impact on the success and feasibility of developing multi-disciplinary guidelines and a Report, outlining a number of recommendations, was provided to the Department. A copy of this Report was provided to Members of the Palliative Care Intergovernmental Forum (PCIF) in August 2003. A final copy of the Workshop report is attached, together with a copy of the Background Paper provided to Workshop participants.

6. Actions arising out of Multi-Disciplinary Guidelines Workshop.

In considering the Workshop's Recommendations the Department and the Palliative Care Intergovernmental Forum were:

- keen that where possible existing work under the NPCP was acknowledged and built upon rather than new systems and structures being implemented.
- Agreed that there is considerable activity within the palliative care community at present and that this activity is focused on research into different models for providing palliative

care, education and training models, and research on aspects of clinical care. The results of a number of these projects are currently in preparation, or will be submitted over the next 12 months and the data would play a significant role informing guideline development and content.

Recommendation 1: That the development of Multi-disciplinary Guidelines for Palliative Care does not go ahead at this stage; but that this issue should remain on the agenda until recommendation three (below) is completed. (Note: The findings of the Workshop also recognised that there was a need to be mindful of overlaps with other guidelines, and the potential for *guideline fatigue*).

As recommended, the development of multi-disciplinary guidelines will not be progressed. It should be noted, however, that multi-disciplinary palliative care guidelines for staff working in residential aged care facilities are currently being developed and will be publicly available in early 2004. An education program will support the dissemination of these Guidelines.

Recommendation 2:

(a) That the NHMRC be approached to have palliative care incorporated into all new clinical practice guidelines;

The Department of Health and Ageing will approach the National Health and Medical Research Council as recommended.

(b) That a palliative care reference group be established to provide guidance on this issue;

The Palliative Care Intergovernmental Forum is an advisory committee whose membership is made up of representatives from the Australian Government and State and Territory governments who work in the area of palliative care. One of the roles of the Palliative Care Intergovernmental Forum is to consider strategic policy issues and provide advice on strategies and alliances that will strengthen the care of the dying across all sectors of the health system, including any associated sector reforms in health, education/training, media, community social support and other areas. Forum Members believe that they are well placed to be able to provide the necessary guidance and that there is no need to establish a separate reference group.

(c) That a statement of principles be developed and made available through Palliative Care Australia (PCA)

In October 2002, the Department convened a meeting of key external and internal stakeholders with an interest in the education of health professionals in palliative care. At this meeting, participants suggested, and the Department agreed, that a national interdisciplinary statement of principles and core values, supported by a suite of educational resources, be developed that could inform the review and development of palliative care education in undergraduate curricula across the relevant disciplines.

Professor Michael Ashby, Professor of Palliative Care, Monash Medical Centre, subsequently developed a draft *Multi-disciplinary Statement of Principles and Core Values* which was endorsed by meeting participants, and formed the basis of a recent tender process. The successful tenderer was a consortium led by the Queensland University of Technology in partnership with Flinders University in South Australia and the Charles Darwin University in the Northern Territory. The consortium will finalise and gain endorsement for the draft

National Multi-disciplinary Statement of Principles and examine, recommend and undertake the development of appropriate resources to support the *Statement of Principles* document.

The Department will consult with Palliative Care Australia, the national peak body for palliative care in Australia, during this process.

Recommendation 3: That a mapping exercise be undertaken of the current clinical practice guidelines and to also include guidelines known to be in development:

The focus of this exercise would be:

- **To map content and identify areas of overlap and gaps related to palliative care**
- **To review the quality of these resources in relation to useability**
- **To explore potential for assisting in the uptake or clinical implementation of these existing resources**
- **To make recommendations to the Department of Health and Ageing on how to improve the uptake of these resources**

In 2001 the Department engaged Flinders University to consolidate an on-line evidence base for palliative care. The benefit of such a resource is to draw together relevant research and learnings for palliative care in Australia, which would in turn improve the accessibility of such information to the sector. The Department is now exploring the enhancement of this system into a broader integrated knowledge, information, education and research resource network. We will consider the potential to address this recommendation within the context of this system's development.

Recommendation 4: That a resource for multi-disciplinary care, including consumer and HCP versions be developed. This resource would cover aspects such as:

- a) **Defining multi-disciplinary care,**
- b) **Function and the role of multi-disciplinary care**
- c) **How to make referrals**
- d) **Who comprised a multi-disciplinary team**

Palliative Care Australia have recently published *Palliative Care Service Provision in Australia: A Planning Guide* which was developed in consultation with the members of Palliative Care Australia, key stakeholders and other organisations. This publication covers some of the issues raised by the Workshop and flags a future discussion paper focussing on Models of Care Delivery. The Department will liaise with Palliative Care Australia on these issues, including around consumer resources.

Recommendation 5: That a “palliative care kit” be developed. This kit would be a resource for the provision of palliative care in any setting and incorporate models, standards, and bring together current resources.

Agree the usefulness of such a kit but believe that issues around maintaining its ‘currency’ would need to be addressed. The Department will consider the potential to progress this recommendation through the broader integrated knowledge, information, education and research resource network outlined under Recommendation 3 above.

Kits already developed or being developed, of which the Department is aware include:

- The resources to support the education of residential aged care staff in the palliative approach that is being developed as part of the *Australian Palliative Aged Care Project*;
- the *Pop-Up Palliative Care Kit* - a palliative care service for rural and remote communities through the dissemination of a kit containing the relevant tools for construction
- the *ACT Hospice Resource Kit*, developed under the Caring Community Project. A package of materials to increase community awareness and understanding and to assist access to palliative care services including:
 - : Palliative care booklet on the dying experience
 - : Directory of appropriate services available in the ACT and Southern NSW region
 - : Brochures on specific topics including access to palliative care, organisations and networks that provide support and care for palliative care users
 - : Fact sheets on subjects relating to palliative care

Recommendation 6: That consideration be given to establishing new approaches to involving key consumer groups, organisations or individuals. For example advocacy workshops, identifying “Champions”

This Recommendation is already met by existing strategies that involve key consumer groups, organisations and individuals, for example, in recognition of the critical importance of a strong consumer and non-government voice in the palliative care sector, the Department:

- currently provides funding of approximately \$300,000 per year to PCA to support it as the peak, national, non-government organisation representing the interests of the Australian palliative care sector. The funding is used to assist PCA to fulfil its role as the organisation in which consensus advice is developed for government and to fund the organisation's recurrent expenses.
- provides funding to support Palliative Care Week nationally, as do State/ Territory governments at jurisdictional level.
- involves relevant stakeholder input at the planning, development, implementation, monitoring and evaluation stages of each initiative

Additionally, the Palliative Care Intergovernmental Forum provides a forum to support the implementation of the National Palliative Care Program at both the Federal and State and Territory level. This includes identifying, monitoring and supporting the needs of special population groups including children and their families and carers. The Palliative Care Intergovernmental Forum meets twice a year and secretariat support is funded by the Australian Department of Health and Ageing.



Palliative care – quality of life for people with a terminal illness, their families and carers

Report on the Workshop on Development of Evidenced Based Multi-disciplinary Guidelines for the Provision of Palliative Care

Held 29th May 2003

Conference Room 1

Department of Health and Ageing

Furzer Street, Woden ACT

Canberra

Prepared for the Commonwealth Department for Health and Ageing

Associate Professor Kate White

Background:

Australian Health Ministers' Advisory Council (AHMAC) endorsed the National Palliative Care Strategy in October 2000. The Commonwealth has made available a total of \$162 million for palliative care throughout the five years of the current Australian Health Care Agreements (1998-2003). Of this, \$151 million has been broadly allocated on a per capita basis to States and Territories for continued service provision, and \$11 million for the Commonwealth to implement a national program of initiatives.

In May 2002, the Commonwealth Government committed a further \$55 million over four years for Commonwealth activities to support improvements in the standard of palliative care offered in local communities.

This total \$66 million funding for national activities, known as the National Palliative Care Program, has provided the opportunity to improve the quality of palliative care through the provision and co-ordination of a national program of initiatives. This national program is being implemented across the following six broad priority areas:

1. Provision of an expanded range of medications for palliative care in the community
2. Assistance for families and increased support to other care networks
3. Education, training and support for the primary care workforce
4. Increasing the range and reach of palliative care services
5. Capacity building in the palliative care research community
6. Performance information development

The Department of Health and Ageing explored the feasibility of developing evidenced based clinical practice guidelines in palliative care for the multi-disciplinary team as a new initiative for palliative care. A workshop was held in Canberra on the 29th May 2003 with key stakeholders to explore the feasibility, justification and potential for evidenced based clinical practice guidelines in palliative care for the multi-disciplinary team. This paper provides an overview of the discussions and recommendations from this workshop.

Purpose of the workshop

The aim of the workshop was to explore the feasibility of developing multi-disciplinary guidelines for the delivery of palliative care to enhance the quality and effectiveness of palliative care service delivery and promote and support partnerships in the provision of care.

Specific Objectives were to:

- Define the need for multi-disciplinary guidelines
- Define the target audience
- Identify barriers to the development of multi-disciplinary guidelines

- Identify strategies to overcome identified barriers

A background paper was prepared to inform the workshop (Appendix One).

Workshop participants

The workshop was attended by palliative care experts, a Palliative Care Australia representative, clinicians with expertise in guideline development and representatives from the Department of Health and Ageing (Appendix Two). A number of key disciplines were represented.

Structure of the workshop

The workshop was run through small and large group discussions focusing on the following key areas:

- What are the opportunities that exist?
- What are the priorities that need to be considered?
- What are the key issues?
- What is the way forward?

Discussions in the small groups were found to be consistent across both groups.

Feasibility/ Timing/Need for Multi-disciplinary Guidelines

Several factors were identified that would impact on the success and feasibility of developing multi-disciplinary guidelines.

Current level of activity within the Palliative Care community

It was identified by the Director of Palliative Care Section, Ms Rita Evans, and a number of participants that there is considerable activity within the palliative care community at present. This activity is focused on research into different models for providing palliative care, education and training models, and research on aspects of clinical care. The results of a number of these projects are currently in preparation, or will be submitted over the next 12 months. This data would play a significant role informing guideline development and content.

Number of clinical practice guidelines recently developed

A number of clinical practice guidelines are either in preparation or recently released that could overlap with multi-disciplinary guidelines. For example:

- Therapeutic guidelines: Palliative care
- Generic cancer psychosocial guidelines
- Guidelines for palliative care in aged care settings
- Acute pain guidelines

The potential for overlap, and “guideline fatigue” is a potential barrier to the success of new guidelines. Workshop participants concluded that a review

of existing guidelines and mapping of content would be needed before being able to fully determine the need for additional palliative care guidelines.

It was identified by the participants that other projects underway had the potential to link, inform or duplicate this activity. For example the Multi-disciplinary Undergraduate Curriculum project may be a project that guideline could link with.

Core principles that would need to be considered

Several core principles were identified as central to reinforcing the goals of palliative care practice. These include:

- Establishing a minimum standard of palliative care for individuals regardless of location.
- Any system, service, development must take into account the needs of communities who may be disadvantaged: for example lower socio-economic, rural, indigenous, or multicultural.
- Education of health and general communities regarding palliative care.

Defining what is multi-disciplinary care

Different views of what constitutes multi-disciplinary care, and whether this is a requirement, or a reality within the palliative care area were expressed during the workshop. It was acknowledged the term was open to different interpretations, both nationally and internationally. It was agreed by workshop participants that there is a need to articulate what multi-disciplinary care is within the context of caring for a palliative care patient.

Recommendations from the Workshop

Recommendation One: The development of Multi-disciplinary Guidelines for Palliative Care does not go ahead at this stage. That this issue should remain on the agenda until recommendation three is completed.

Recommendation Two: The NHMRC be approached to have palliative care incorporated into all new clinical practice guidelines. A palliative care reference group could be established to provide guidance on this issue. In addition, a statement of principles be developed and made available through Palliative Care Australia.

Recommendation Three: A mapping exercise be undertaken of the current clinical practice guidelines and to also include guidelines known to be in development:

The focus of this exercise would be:

- To map content and identify areas of overlap and gaps related to palliative care
- To review the quality of these resources in relation to useability
- To explore potential for assisting in the uptake or clinical implementation of these existing resources
- To make recommendations to the Department of Health and Ageing on how to improve the uptake of these resources

Recommendation Four: To develop a resource for multi-disciplinary care.

This brief resource would cover aspects such as:

- Defining multi-disciplinary care,
- Function and the role of multi-disciplinary care
- How to make referrals
- Who comprised a multi-disciplinary team
- Consumer and HCP versions

Recommendation Five: That a “palliative care kit” be developed. This kit would be a resource for the provision of palliative care in any setting and incorporate models, standards, and bring together current resources.

Recommendation Six: Consideration be given to establishing new approaches to involving key consumer groups, organisations or individuals. For example advocacy workshops, identifying “Champions”

Background paper prepared by Associate Professor Kate White for the Commonwealth Department of Health and Ageing:

Australian Health Ministers' Advisory Council (AHMAC) endorsed the National Palliative Care Strategy in October 2000. The Commonwealth has made available a total of \$162 million for palliative care throughout the five years of the current Australian Health Care Agreements (1998-2003). Of this, \$151 million has been broadly allocated on a per capita basis to States and Territories for continued service provision, and \$11 million for the Commonwealth to implement a national program of initiatives.

In May 2002, the Commonwealth Government committed a further \$55 million over four years for Commonwealth activities to support improvements in the standard of palliative care offered in local communities.

This total \$66 million funding for national activities, known as the National Palliative Care Program, has provided the opportunity to improve the quality of palliative care through the provision and co-ordination of a national program of initiatives. This national program is being implemented across the following six broad priority areas:

1. Provision of an expanded range of medications for palliative care in the community
2. Assistance for families and increased support to other care networks
3. Education, training and support for the primary care workforce
4. Increasing the range and reach of palliative care services
5. Capacity building in the palliative care research community
6. Performance information development

The Department of Health and Ageing is exploring the feasibility of developing evidenced based clinical practice guidelines in palliative care for the multi-disciplinary team as a new initiative for palliative care. Before moving to an open tender process, the department is seeking to consult with key experts on a number of areas related to this proposal. This paper provides background information for the consultation process.

Purpose of this paper

The aim of this paper is to provide background material for the workshop to be held on the 29th May 2003. The content of the paper addresses key areas for potential guidelines in palliative care to be covered in the workshop. The content is not conclusive, and workshop participants are invited to comment on, delete or add to the content of this document.

Role of Evidence-Based Guidelines

Evidence based guidelines (EBG) are systematically developed statements, which assist in decision making about appropriate healthcare for specific clinical conditions¹. They aim: to improve the diagnosis and treatment of a particular condition; to reduce variations in health care practice and thereby improve the quality of patient care in clinical practice; and to encourage further research. Evidence-based guidelines are based on good research evidence of clinical effectiveness. They can form the basis for the standards against which comparative audit will be conducted.

In addition, EBG (also referred to as clinical practice guidelines see appendix two for definitions) can be:

- Decision tools that close the gap between current and optimal practice²,
- Mechanisms to improve the quality of health care and decrease costs³,
- Processes to operationalise the implementation of evidence based practice⁴.

It is essential to highlight that EBG are aimed at supporting, not replacing, clinical decision making. To this end they are not designed to be prescriptive, but provide a tool to assist the clinician and patient in achieving optimal treatment. Evidence based guidelines are most widely recommended when there is evidence of inconsistency in clinical practice, less than desirable patient outcomes, or evidence to support interventions not currently being adopted. That is, when there is a 'gap' between current clinical practice and evidence based practice.

In the past decade evidence based guidelines have become widely adopted in a number of areas in healthcare. Reviews have shown that the development and implementation of EBG have led to significant improvements in clinical practice and patient outcomes^{5,6}.

Defining Palliative care

It is beyond the scope of this paper, and not helpful to the overall objectives, to cover the current debate regarding definitions of palliative care. The World Health Organisation definition of Palliative care has been widely adopted and is used as a guiding definition for this document.

Palliative care is an approach which improves the quality of life of patients and their families facing life-threatening illness, through the prevention and relief of suffering by means of early intervention and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual problems.

Palliative care:

- Provides relief from pain and other distressing symptoms;
- Affirms life and regards dying as a normal process;
- Intends neither to hasten nor 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 earlier in the course of illness, in conjunction with other therapies that are intended to prolong life. 7

Palliative care may be provided in a number of settings: home, acute hospital, hospice, palliative care unit, or aged care facilities. Over the past two decades there has been a substantial growth in the development of specialist palliative care services across Australia. However, it is widely recognised that the majority of Australians will receive palliative care from either their generalist health care providers (for example: general practitioner, community nurse) or their disease specialist (for example: neurologist, oncologist, respiratory physician). These individuals may seek additional support from specialist palliative care service providers.

Need for Palliative Care in Australia

There are limited data on the actual number of Australians that are currently receiving or may require access to palliative care. A number of papers have developed estimates based on figures for the proportion of the population over the age of 65 years and projected cancer incidence and mortality^{8,9}. These figures often do not take into account individuals in younger age groups, or those with diseases other than cancer, such as HIV/AIDS, end stage neurological, cardio-respiratory or renal disorders. Conservative estimates suggest that a significant proportion of Australians will require access to palliative care, some authors suggesting it to be as high as 60% of people suffering a terminal illness¹⁰.

Data from the Australian Institute of Health and Welfare reveal that leading causes of death for men and women age 44 and over are cancer, heart disease and respiratory diseases¹¹. Heart disease in men, and breast cancer in women are the leading single cause of premature death in Australia¹¹. Cancer is the third major cause of deaths for children aged 1 to 14 years, after accidents and poisonings¹¹. While there are clear limitations in drawing

solely on these figures, they do support the need for palliative care to be available to these populations.

Population numbers are but one factor that requires consideration. The burden of illness is must be taken into account when considering need for palliative care in an Australian population. A number of diseases may be small in number, but have a substantial impact on quality of life for both patient and family. These conditions are often amenable to symptom management, and palliative care can make a significant difference to the individual and their family. For example, motor neurone disease and Huntington's Chorea. This supports the need for palliative care to be widely available in the broader health community, not limited to cancer services, or specialist palliative care services.

Need for guidelines if palliative care

A number of reasons support the need for the development of guidelines for palliative care:

- Need for improved access to palliative care practice in the community
- Evidence suggest that standards of palliative care practice are variable
- Misconception there is a lack of scientific basis for palliative care practice
- Need to develop consistency in palliative care practice
- Support for the broad implementation of palliative care into clinical practice
- May assist in overcoming barriers to early implementation of the principles and practices of palliative care
- Engage the health community in the delivery of palliative care through the development of the guidelines and subsequent implementation

There are mixed reports regarding the quality of palliative care in Australia. Limited research guides this information, and much is anecdotal. Despite this there is a strong argument from the both health professionals and the public for improved palliative care in Australia. To move forward there is need to establish clear recommendations for palliative care practice, that are based on a rigorous review of current research.

In addition to the growth of specialist palliative care services, the Australian community has become better informed regarding palliative care and expectations of care associated with the final phase of life. Education in palliative care has not always kept pace with these developments, with palliative care courses for health professionals not being established till many years after services were created. The gap between community expectation and palliative care education and knowledge base may be a contributing factor in the inconsistent palliative care practices.

This gap in knowledge is reinforced by the misconception that there is a lack of scientific evidence to support palliative care practices. Similarly, it was

commonly held view that there was no scientific evidence to support psychosocial care for women with breast cancer. A number of reviews highlighted level I and II evidence to the contrary, and these led to the development of the *Guidelines for psychosocial care of women with breast cancer*. Often the level of available evidence is not known until the systematic reviews are undertaken.

There is little doubt that unrelieved suffering has a profound impact on an individual's quality of life. Equally evident is that palliative care can reduce this suffering and maintain or improve quality of life for individuals with progressive disease¹². This reason in itself provides a strong argument for the development of guidelines for palliative care practice.

Potential audience

In developing guidelines the potential target audience must be clearly articulated. There are a number of considerations for the proposed guidelines:

- Which audience(s) will achieve the maximum impact in relation to improved patient outcomes?
- Where are the majority of palliative care patients cared for in Australia?
- Who provides this care?
- What does a multi-disciplinary team consist of?
- Is it feasible to develop guidelines for different disciplines?
- Distinguish between target audience and potential other audiences
- Do the guidelines target generalist health care providers or specialist palliative care providers?
- Is this mutually exclusive?
- Does the target audience include consumers (patients and/or families)?
- How will these guidelines articulate with current guidelines (for example Acute Pain Guidelines)?

These factors will need to be made clear in the tender document, and are for discussion during the workshop.

Potential aims for developing Multi-disciplinary Guidelines for Palliative Care

Suggested overall aims for the guidelines could include:

- To improve the quality of palliative care
- Assist health care professionals in treatment decisions related to palliative care practice
- Assist health care professionals and patients in the transition to palliative care
- Educate the healthcare professionals regarding palliative care practice

Workshop participants are invited to add additional objectives to this list, and identify ones they would not support.

Suggested content

The content of the guidelines will be dependent on a number of factors. Outlined below is list of potential broad headings:

- Advanced care planning
- Managing the transition to palliative care
- Symptom management
- Psychological care
- Spiritual care
- Social support
- Ethical concerns
- Community support
- Practical needs
- Resources
- Implementation of guidelines

Challenges for Evidence Based Guidelines in Palliative Care

The development of palliative care guidelines may or may not contribute to improved palliative care outcomes. Workshop participants are asked to consider the following questions:

1. Is it feasible to develop EBG in palliative care?
2. Would such guidelines be considered value for money?
3. Are they likely to be adopted widely?
4. If not are there reasonable strategies to overcome these barriers?

Feasibility

Participants at the workshop will be asked to consider the overall feasibility of developing palliative care guidelines. Specifically:

- Is there sufficient research evidence to support the development of guidelines?
- Will the guidelines be readily taken up by the target audience(s)?
- Is there support for the guidelines in the broad health community?
- Will guidelines for palliative care practice lead to improved patient outcomes?
- How will these guidelines add to/build on existing guidelines or those in development?

Value for money?

Despite a body of evidence that supports the development of EBG, there are factors that can limit the effectiveness of guidelines. Guideline development can be costly financially. In addition to costs in development, production

dissemination, implementation strategies and updating costs need to be taken into consideration. For this reason workshop participants are asked to carefully consider the potential benefits and feasibility of this project. Being mindful of the limited resources available the question needs to be asked “will this be good value for money?”

Barriers to Guideline Implementation:

There is a growing volume of literature that explores barriers to implementing EBG. In considering these guidelines, it should be noted that there have been number of guidelines developed recently, or under way where there may be potential overlap in some areas, though not all. Concerns have been raised by some health disciplines about how to manage the volume of clinical practice guidelines that are currently being developed.

The workshop participants are asked to consider the following:

- If these barriers are sufficient to prevent the project progressing?
- Are there strategies to address these concerns?
- Should they be incorporated into the tender document? or
- Should applicants be asked to identify how they would address these issues?

Levels of evidence: role of consensus based recommendations

Evidenced based guidelines have evolved over the past decade. Initially, where limited evidence was available and there was a need to provide some guiding recommendations advisory groups that comprised clinical experts established consensus based recommendations. More recently there has been shift away from this approach, with a strict reliance on evidence that can be reviewed.

In the area of palliative care there may be areas that are considered common and accepted practice, based on clinical expertise, where consensus could be achieved, but there is not research evidence to support it. Should this be excluded from the guidelines development? That is the NHMRC levels only be used as the guiding evaluation. Should qualitative and descriptive studies be excluded, or a system for inclusion be incorporated?

Moving Forward: Approaches to Overcome the Challenges

There are a number of strategies that can be implemented to address potential barriers that could be incorporated into the Tender Brief. Participants are asked to add to these suggestions.

The project incorporates three identifiable phases with outcomes linked to each phase:

1. Development of guidelines
2. National consultative process and finalising of guidelines
3. Identification of Implementation strategies

Other factors to be considered include:

- Will the tender brief specify the composition of the research team?
- Establishment an advisory group
- Identification of strategies that would achieve “buy in” from relevant groups
- Will the project include funding for dissemination strategies?
- Role of Implementation Workshops
- Consumer versions
- What is a realistic timeframe for completion of this project?

References

1. Institute of Medicine, Clinical Practice Guidelines: Direction for a new program. DC: National Academy Press, 1990.
2. Handley, M., Stuart, M., Kirz, H. An evidence-based approach to evaluating and improving clinical practice. HMO Practice 1994; 4:75-83.
3. Basinski, A Evaluation of clinical guidelines. Canadian Association of Medicine Journal 1995; 153:1575-1581.
4. Mead, P. Clinical guidelines: promoting clinical effectiveness or a professional minefield. Journal of Advanced Nursing 2000; 31:110-116.
5. Grimshaw, J., Russell, I., Effect of clinical practice guidelines on medical practice: a systematic review of rigorous evaluations. Lancet 1993; 342:1317-1322.
6. Effective Health Care Bulletin. Implementing clinical practice guidelines. York: University of York, 1994.
7. World Health Organisation 2002 Definition for palliative care. <http://www5.who.int/cancer/main.cfm?p=0000000427> Accessed 14/05/03
8. Department of Health and family Services palliative care: Background for A National Strategy for palliative care in Australia. ACT: Commonwealth of Australia 1998.
9. NSW Health Working Party Report of NSW Health Palliative care Working Party, NSW: NSW Health, 1993.
10. Department of Human Services, Palliative Care in Victoria: A vision. Vic: 1995
11. Australian Institute of Health and Welfare, Trends in Deaths, ACT: Australian Institute of Health and Welfare, 2002.
12. Hearn, J., Higginson. I, Do specialist palliative care teams improve outcomes for cancer patients? Palliative Medicine, 1998; 12:317-332.
13. Grol, R., Dalhuijsen, J., Thomas, S., Veld, C., Rutten G., Mokkink, H., Attributes of clinical guidelines that influence use of guidelines on medical practice: a systematic review of rigorous evaluations. BMJ 1998; 317(7162):858-861.
14. New Zealand Guidelines Group Handbook for the preparation of explicit evidenced based clinical practice Guidelines. New Zealand: New Zealand Guideline Group 2001.

Workshop Participants:

Dr Jane Turner	University of Queensland
A/P Phyllis Butow	University of Sydney
Mrs Heather Wain	Chair, National Breast Cancer Foundation
Ms Isobel Hubbard	Occupational Therapist and lecturer Newcastle University
Dr Mary Brooksbank	Royal Adelaide Hospital
Dr Bruce Rumbold	La Trobe University
Ms Janeane Harlum	Braeside Hospital NSW
Dr Kevin Yuen	Cottage Hospice and Royal Perth Hospital
Ms Lidia Ross	Palliative Care Australia

Department of Health and Ageing

Ms Rita Evans	Director Palliative Care Section
Ms Jeanne Mansbridge	Palliative Care Section
Ms Wendy Cook	Palliative Care Section
Mr Martin Mullane	GP Access Branch
Ms Jennie Della	Primary Care Policy Section
Ms Eva Mehakovic	Aged Care Division

Facilitator:

Associate Professor Kate White Edith Cowan University

NATIONAL UNDERGRADUATE MULTIDISCIPLINARY PALLIATIVE CARE CURRICULUM FOR HEALTH PROFESSIONALS

INTRODUCTORY DISCUSSION DOCUMENT DRAFTED FOR THE COMMONWEALTH DEPARTMENT OF HEALTH AND AGEING

Dying is not a subspecialty of medicine; it is our common lot...[T]he aim is not a set of rigid structures committed to their own survival and enlargement, but a concentration of effort on achieving lasting change on the circumstances of death in post-industrial societies.¹

SUMMARY

Most health professionals will be involved in care and decision-making at the end of life for part or all of their working lives, and some will have a special interest in this area of care, or devote their careers to it. Provision of high quality palliative care across the Australian health care system is a major health policy priority, as set out in the *National Strategy for Palliative Care in Australia 1998-2003*. Palliative care is therefore more than just a peripheral special interest group in health care, it is a “centre stage” issue for everyone. It is of necessity interdisciplinary, focusses on the whole person and the family, and seeks to inform and empower the community to deliver the best care and support at the end of life. None of this can happen without laying the foundations in the undergraduate years of professional training. The attitude-knowledge-skill mix required to do this work effectively should be explicitly present in all undergraduate curricula. However, self evidently the content must be appropriate to the role(s) of each profession in the provision of palliative care services.

This paper sets out, for wide consultation, the values and learning domains for palliative care education across the health professionals. It also emphasises the need for experiential learning, and clinical teaching by specialist palliative care workers. In addition it recognises teaching of relevance to palliative care practice in other areas of the course (eg communication skills, ethics, basic sciences), and the valuable contributions made by other disciplines, both specialist and generalist.

INTRODUCTION

The Commonwealth Department of Health and Ageing has recognised the importance of placing palliative care in Australia firmly on the national health agenda. To this end it has produced a *National Strategy for Palliative Care in Australia 1998-2003*,² after wide consultation with the field itself, the rest of the health services, and the community. As a result of these consultations, Objective 1.4 of the Strategy aims to:

1 Alistair Campbell. *An Ethic for Hospice*. Address to first national conference of Australian Hospice Association. Adelaide, 1990.

2 Available through the department’s website at www.health.gov.au. See also the companion document *Palliative Care. Background for A National Strategy for Palliative Care in Australia*. Commonwealth Department of Health and Family Services, Canberra, 1998.

Support the educational needs of the specialist palliative care workforce (medical, nursing and allied health) to meet consultancy and complex care needs; enhance the skills and expertise of primary health practitioners (including general practitioners and nurses) in providing care for people who are dying and their families; and support and enhance the skills of both groups in working collaboratively across professional boundaries.

The importance of educating the professions, and informing everybody – professions and the whole community - about what palliative care is, how it is done and how services are accessed, has been a major recurring theme in health policy and service development concerning end of life care all over the world.

A meeting arranged by the Department in Canberra on 15 October 2001, brought together representatives of the nation's health sciences educators, with specialist palliative care practitioners and academics, to discuss development and implementation of the education strategy. The meeting specifically sought to address the feasibility of developing a national undergraduate interdisciplinary palliative care curriculum for health professionals. There was agreement that there was a need for more to be known about what is taught at the moment, and that a discussion paper setting out the agenda, values and broad content of such a document should be commissioned.

In response to the second recommendation, this paper sets out the elements of palliative care, its core values and major learning domains,³ which could then form the basis for such a curriculum, after further appropriate consultations. It also makes certain recommendations about educational process.

BACKGROUND

The aim of palliative care is to improve comfort and quality of life for those who face death from progressive incurable diseases. Inherent to this endeavour is an understanding that there is an identifiable and acknowledged dying process, resulting in a death which is anticipated rather than sudden and unexpected.

Palliative Care is defined as follows by Palliative Care Australia:

Palliative Care is specialised health care of dying people which aims to maximise quality of life and assist families and carers during and after death.⁴

3 This paper incorporates many elements of the Australasian Undergraduate Medical Palliative Care Curriculum (1997) written for the Australia and New Zealand Society of Palliative Medicine (ANZSPM) by a group consisting of Michael Ashby (Monash), Mary Brooksbank (Adelaide), Paul Dunne (Tasmania) and Rod Macleod (Wellington). See also the Canadian Palliative Care Curriculum (1991) by Dr Neil Macdonald for the Canadian Committee on Palliative Care Education, and Palliative Medicine Curriculum. Association for Palliative Medicine of Great Britain and Ireland.

4 Palliative Care Australia. Strategic Plan 2000-2003. The longer definition of Palliative Care adopted by the Australian Association for Hospice and Palliative Care in 1994 was:

A concept of care consisting of coordinated medical, nursing and allied services for people with terminal illness:

- delivered in the environment of patient's choice
- provides physical, psychological, emotional and spiritual support for patient, family and friends
- addresses grief and bereavement before and after death.

The evolution of modern palliative care has been driven by two principal forces: firstly, the misery of poor pain and symptom control for terminally ill people, and secondly, the psychological, emotional, spiritual and social insights which have been gained from work in the behavioural and social sciences, and the humanities. This has been accompanied by greater community, political and media interest in death and dying issues. These have concerned cancer, euthanasia, high profile requests for assistance to die with chronic neurological conditions such as motor neuron disease, and HIV/AIDS. The rising incidence of cancer and proportion of the population who die of cancer has had a substantial influence on the scale and development of palliative care services. Cancer patients account for 80-90% of adults who receive palliative care in Australia, but there is growing interest in applying the principles of palliative care to all those who face death as a result of non-malignant conditions, and these referrals are rising for most services.

Palliative care delivery therefore has a central clinical focus, embedded in a wider social agenda involving the empowerment and resourcing of patients, families, carers, volunteers and communities. As such it is a broadly based activity, involving a partnership between health workers and the public – it is everybody's business.⁵

CORE VALUES

Here are some of the main values that underpin the proper care of people who are reaching the end of life. These values should be discussed with students and developed throughout undergraduate courses.

- Dying is a natural part of living, and death is an inevitable consequence of having life. No amount of medical progress can change this fact. Whilst we have a duty to try to preserve our patients' lives, this does not mean that we are obliged to treat the dying as if they can be cured.
- Dealing with death and dying is an intrinsic part of health care but we should also guard against over-medicalisation of the process of dying. Clinicians must be able to recognize a patient who is dying, and the benefits and burdens of any treatment offered at that time. Distinguishing a sick patient (unexpected change/potentially reversible causes) from a dying patient (anticipated change/no disease modification possible) is an important skill.
- Provision of the best possible pain and symptom relief in the clinical circumstances is both a patient's right and a health carer's duty. Inadequate expertise is not a defence of sub-optimal care as specialist help, support and education are available.
- Appropriately negotiated treatment abatement and administration of symptom relief do not constitute causing death.
- Grief, loss and bereavement are intrinsic parts of all of our lives. An understanding of the patterns of human grief behaviour and the ability to understand and support grieving people is an important skill for all health professionals. This loss and grief includes not just the family and friends of the dying person, but the dying person themselves. Clearly

⁵ For an exposition of this in the context of a broad public health approach to palliative care, see Allan Kellehear's book Health Promoting Palliative Care. Melbourne: Oxford University Press, 1999.

loss and grief affect health professionals and training must include how to recognize and deal with this in a healthy way.

- A person's dying days are of just as much value as their non-dying ones.
- A person has a right to have their beliefs, needs and wishes recognised and respected at all stages of life, including when they are dying. Care should be based on viewing the patient's needs in the context of the whole person rather than a series of (medically defined) parts.
- Care is always focused on the needs and wishes of individual patients. However, due acknowledgment of the patient's key relationships (family and friends) and social context is also important. Few people live in a complete social vacuum and psychological, social, bereavement and other practical support should be offered (where appropriate, and according to resources available) to family, friends and carers.
- Wherever possible, people should have the option of receiving palliative care in the setting that most suits their needs and wishes: home (including nursing home), hospital or specialist hospice/palliative care unit.
- Access to palliative care should be based on patient and family need, rather than solely on prognosis and/or disease type.⁶

This approach avoids the need to talk of one tightly-defined “philosophy” of palliative care. It is also then possible for these values to permeate any service model, depending on local resource availability, needs and wishes. In other words the operationalisation of palliative care values is not solely defined in terms of specialist individuals or teams, nor are they specific to any particular discipline.

Some of these values are generic to health care: palliative care does not have a monopoly on caring and patient rights promotion. However, the integration and acceptance of death and grief into the health care system is a fragile ongoing process, and therefore a major focus of palliative care practice and education.

WHO NEEDS IT?

The following professions and health disciplines are the major contributors to the provision of palliative care:

- doctors (general practitioners and specialists from many disciplines)
- nurses (including those with expertise in a range of specialist areas)
- physiotherapists
- occupational therapists
- dietitians
- speech therapists
- pharmacists
- social workers
- pastoral care/chaplaincy

⁶ Higginson I. Palliative care: a review of past changes and future trends. *Journal of Public Health Medicine.* 1993;15:3-8.

- psychologists

All health workers will be involved in palliative care in the acute hospital setting where they spend crucial formative terms early in their professional careers. However, some exposure will usually already have occurred during undergraduate clinical placements, regardless of whether they formally study palliative care or not. Junior staff from all disciplines will be attending critically ill and dying patients throughout their clinical hospital terms, and are especially exposed during out of hours and emergency work. They all therefore need to be equipped to cope with this demanding aspect of their early clinical work.

Most practitioners will continue to deal with death, dying, loss, grief and life-threatening situations throughout their careers, and will need to be open to the life-long learning necessary to fulfill this aspect of their generalist role. It is also desirable for undergraduate studies to sow the seeds that lead some graduates to look at future specialist palliative care training.

There will always be a need for a generalist/specialist mix of health personnel to be involved in palliative care delivery,⁷ especially in the Australian context, where geography and demographics alone mandate this.

There is clearly a need for all those who work in aged care and rehabilitation services to be prepared for the large amount of care and decision-making at the end of life which is required in those environments.

Finlay and Jones have described three distinct but interconnected aspects of palliative care: the palliative approach,⁸ which should be a core skill-base of all clinicians, palliative interventions, which are often carried out by other medical or allied health specialists (eg radiotherapy, surgery and physiotherapy) and specialist palliative care, which is delivered by specialist clinicians in the context of a dedicated interdisciplinary team, or as a consultative service to other health care providers, units or teams.

There is, therefore, an overwhelming case for all health students to be equipped at least to the level of the palliative approach.

WHAT DO THEY NEED?

Practitioners need to be able to recognise a life-limiting disease, and imminent death, as important preludes to physical symptom management. They need to address the following questions with their patients and colleagues in order to frame the approach to care:

⁷ For discussions on the relative merits of specialist versus generalists in the provision of palliative care see several chapters in: Parker J and Aranda S. Palliative Care: Explorations and Challenges. Rosebery, NSW: MacLennan and Petty, 1998.

⁸ The palliative approach is relevant to all patients with incurable conditions. It emphasises the importance of considering psychosocial and spiritual aspects as well as the purely physical. It includes consideration of family and domestic carers. Most specialities and all general practitioners look after patients with life threatening disease; attention to the patients' concerns and fears can guide management and ensure appropriate interventions. A palliative approach should be a core skill of every clinician, who may seek expert specialist help to ensure the best possible quality of life for the patient. Finlay IG and Jones RVH, Br Med J 1995; 311:754

- What are reasonable goals in comfort, function and (maybe) life expectancy?
- Have reversible processes been explored when there are changes in the patient's condition?
- Is this an expected or unexpected change?

They need to be comfortable with appropriate revision of goals of care from curative to palliative and eventually terminal modes,⁹ and some familiarity with the ethical and legal arguments involved.

As with all subjects and professional sub-specialties, it is not expected that a new graduate should be an expert in palliative care. However, an openness to reflect on and learn about the care of the dying, together with some basic core attitudes, knowledge and skills are required. By the time of graduation every student (with varying content and emphases, depending on discipline) should have an awareness of the basic principles which underpin the palliative approach, in the topics set out below.

General Clinical

- Pain
- Nausea and Vomiting
- Respiratory Symptoms
- Bowel Care
- Mouth and Skin Care
- Lethargy, Poor Appetite, Weight Loss
- Cognitive, Mood and Sleep Disorders (esp delirium and depression)
- Terminal Care
- Home Care
- Medical and Nursing Duties After Death
- Communication Skills with:
 - Patients
 - Families
 - Other team members
 - Referring colleagues, units or teams.
- Ethics and Medical Decision making at the End of life
- Interdisciplinary Team Work and Volunteers

Disease Specific

- Oncological Emergencies
- Non-Malignant Conditions
- AIDS
- Paediatrics

Psychological, Social, Spiritual

- Psychological Care
- Social Care
- Spiritual and Pastoral Support
- Family support: basic approaches to family dynamics and case work

⁹ Ashby M and Stoffell B. Therapeutic ratio and defined phases: proposal of an ethical framework for palliative care. British Medical Journal 1991;302:1322-1324.

- Grief and Bereavement
- Multicultural and Ethnic issues
- Emotional Self Care for Health Professionals¹⁰

If these domains are divided roughly, albeit artificially,¹¹ into biomedical, psychological and social, it is clear that doctors and nurses will need in depth learning in the biomedical domain, allied health personnel will ‘cherry-pick’ the biomedical aspects they need for their roles, and all should embrace the social and emotional aspects of care. Obviously, social and pastoral care workers will concentrate on the psychological, social and spiritual domains. Clearly, all disciplines will need to have some understanding of all the domains, but also need to be clear, in the interdisciplinary setting, of which core duties, tasks and responsibilities only their discipline can fulfil, and those which they share with other disciplines.

In palliative care services, doctors and nurses have an unusually high degree of involvement in patients’ social, emotional and spiritual care. They need to be equipped to do this, and to know when to consult with, or hand over to, those who have specialist counselling/psychotherapeutic training (ie, social and pastoral care workers, psychologists and psychiatrists, where appropriate and available).

In addition, workers from all disciplines need to be comfortable with the following:

- Seeing the patient as a whole and not just their (professionally-defined) part.
- Contribution to effective care planning, whether this is in the community or an inpatient setting.
- Active and effective participation in patient discharge or transfer planning (including transfer from any site of care to another, not just discharge from hospital).

PERSONAL DEVELOPMENT

Palliative care education also offers some important opportunities for personal growth and learning. Meeting dying people and their carers, learning how to accompany them and sit with their suffering, loss and grief, can be both challenging and enriching.

MacLeod and James¹² have argued that learning palliative care offers an important opportunity for a broader reflection on professional and personal development:

Given the personal nature of the knowledge on which practice is based, there is a case for arguing that the issue in palliative care education is not one of learning about palliative care nor indeed one of learning in palliative care but is one of learning through palliative care.

MacLeod¹³ has also studied how doctors learn to care, and emphasised the significant role of intimate personal experience in this process.

¹⁰ Australasian Undergraduate Medical Palliative Care Curriculum (1997) written for the Australia and New Zealand Society of Palliative Medicine (ANZSPM).

¹¹ The discomfort of Cartesian mind/body dualism in modern palliative care discussions is acknowledged!

¹² MacLeod R and James. Teaching Palliative Care; issues and implications. Published for the Macmillan Education Centre of the Dorothy House Foundation by the Patten Press, Penzance, Cornwall, 1st Edition 1994.

Palliative care learning and experience offer excellent opportunities to emphasise the importance of reflective practice in continuing professional development and life-long learning:

The key to lifelong, effective learning is not to be found in advice about how to learn but rather in how to manage the learning process.¹⁴

Maddocks¹⁵ has emphasised the need to address the practitioner's personal role in caring and communicating. Any palliative care course should therefore aim to help health students to develop their own individual caring style in a healthy and supportive environment.

This personal dimension can also make a substantial contribution to the rest of the student's general professional development, and both complement and reinforce the teaching and experience in the rest of the curriculum.

HOW TO TEACH IT?

Educational technique and process is largely a matter for individual schools, but it is recommended that emphasis be given to:

- Experiential teaching consisting of visits to inpatient hospice/palliative care units, hospital consultative services, and community-based palliative care services. There should be ample opportunity for interaction with patients and family, and to see a palliative care practitioner at work. Debriefing and discussion should be an integral part of the visit/placement program, with both supportive and educational objectives.
- Active rather than passive techniques (eg problem based learning - PBL, discussion, role play in a safe environment, before directly facing some of the difficult issues in practice). Universities which are making extensive use of PBL and this gives a good opportunity for palliative care problems to be included.
- Group learning to foster cooperation.
- Horizontal integration. Specialist palliative care teachers should be aware of what areas of relevance to palliative care are being taught by colleagues in other disciplines.
- Vertical integration; there should be a coordinated step-wise approach evident throughout the course, with the following emphases:
 - early years: attitudes and ethics
 - middle years: knowledge: basic science and clinical
 - final year: skills, practical management.

¹³ MacLeod R. On reflection: doctors learning to care for people who are dying. *Social Science and Medicine* 2001;52:1719-1727

¹⁴ MacLeod R. Personal communication.

¹⁵ Maddocks I. *Teaching the therapeutic power of personality. Medical Journal of Australia* 1990;152:2-3.

- Ethical and psychological/social considerations should be interwoven into all aspects of teaching.
- It is desirable to move towards an integrated approach to the teaching of pain, with coverage of both acute and chronic non-malignant pain as well as palliative care and cancer pain.
- The university's responsibility (shared with hospitals) should continue during the early postgraduate years. Wherever possible education should be linked to the clinical functions of a teaching hospital palliative care consultative service.
- Clinical teaching should be undertaken by specialists in the area, with support from other non-palliative care specialist practitioners who have special interests in the area.

ASSESSMENT AND EVALUATION

This will need to be developed with creativity and sensitivity. Assessment has the danger of highlighting the readily measurable, over-emphasizing detail rather than promoting essential aspects of competence. All examinations have the danger of negatively affecting the student's experiential and attitudinal learning process, which are essential aspects of palliative care education.

Face to face viva or OSCE (Observed Structured Clinical Examination) techniques, with simulated clinical content, are promising and may have advantages over written examinations, particularly with regard to assessing approaches to care and skills.

CONCLUSION

Evaluation of present palliative care education across the professions and promulgation of a national curriculum as a broad learning agenda is a timely and important venture, and may go some way to redressing the present educational unevenness within and across professions.