

# **The effectiveness and appropriateness of a palliative approach to care for people with advanced dementia: a systematic review.**

## **SYSTEMATIC REVIEW PROTOCOL SUMMARY**

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## OBJECTIVES

The overall objective is to establish best practice in relation to palliative care for people with dementia. Specifically, the following questions will be addressed:

- What types of end-of-life care are appropriate for people with advanced dementia?
- Is a palliative approach an effective way to manage end-of-life care in people with dementia?
- Is case conferencing an appropriate process for managing the introduction of palliative care?

## BACKGROUND

The provision of adequate and appropriate care for people with dementia is a significant and growing challenge in Australia and many other societies. These pressures are scarcely likely to decrease over time as Australia's (and much of the developed world's) population continues to age, and the corresponding number of people with dementia continues to rise. The most recent available Australian figures estimate that 175,000 Australians are currently living with dementia and their care needs need to be managed effectively and appropriately [1]. It is well documented that people with advanced dementia often do not receive adequate or appropriate end-of-life care and are not afforded options, such as palliative care, that are commonly offered to people dying from cancer [2].

Palliative care is sometimes described in the words of the earlier (1999) definition by the World Health Organisation which states that "*palliative care is total care of patients whose disease is not responsive to curative treatment...*" [3]. Later, in 2003, palliative care was defined as [4] "*an approach which improves the quality of life of patients and their families facing life threatening illness through prevention and relief of suffering by means of early intervention and impeccable assessment and treatment of pain and other problems – physical, psychosocial and spiritual*". The earlier definition would perhaps suit the purposes of defining palliative care for people with dementia better than the later definition, with the use of the words 'not responsive to curative treatment' rather than 'life threatening illness'.

Most commonly in the past, palliative care has only been offered to patients in the final stages of death from cancer [5]. Statistics from the UK indicate that approximately 95% of all patients receiving specialist palliative care in a hospice environment have a diagnosis of cancer [5]. However, many studies [6, 7] recommend the expansion of the palliative care model to other patient groups requiring end-of-life care.

Kristjanson et al. [8] distinguish between three different types of palliative care: (a) specialist palliative care services that take primary responsibility for the care of the person, directly or indirectly, and involve a broad range of disciplines, (b) palliative care interventions that address particular distressing symptoms and include palliative radiotherapy, surgery and anaesthetic techniques of pain relief, and (c) a palliative approach that aims to improve quality of life but does not necessarily require a specialist palliative care

service taking over the primary responsibility for care. This approach would allow for the utilization of a specialist palliative service when problems arose while day-to-day care planning would stay with the current care providers. A palliative approach is said to be most applicable to older people dying from non-cancer conditions [8], such as dementia, allowing the person to remain in the environment they are already living in.

A report from the World Health Organisation [9] suggests that palliative care had traditionally been viewed as care at the end of the disease process, while a better way may be to view palliative care as starting earlier and concurrently with potentially curative treatment, thus offering support over a longer period of time for people with serious chronic illness(es) and unpredictable times of death. In this model, palliative care would be a smaller component at commencement of care but gradually become a bigger focus until towards the end of the person's life when it would be the dominant model of care.

A WHO study in 2004 to determine the palliative care needs of older people in Europe [3] found significant unmet needs in the areas of pain management, issues around non-cancer illnesses, in particular heart disease and dementia, multiple problems of ageing, concerns about communication and patients centred care, and preferences for place of care and place of death. The study authors concluded that many of the general issues of palliative care for people with cancer, namely the need for good symptom control, communication, and coordinated care, would be similar for people with serious chronic illnesses (and dementia).

In 2004, a set of *Guidelines for a Palliative Approach in Residential Aged Care* was developed and a similar set of guidelines are currently being developed for use in community settings. The *Guidelines for a Palliative Approach in Residential Aged Care* was sent to all Australian residential aged care facilities (RACFs) in 2004, as part of the Australian Palliative Residential Aged Care (APRAC) Project. These *Guidelines* were updated in 2006 and are said to be the first palliative care guidelines developed for residential aged care settings in the world [10]. Currow and Hegarty [11] suggest that the *Guidelines* encourage a shift in thinking; from palliative care only being associated with end-of-life care, to being applied earlier in the trajectory, so quality of life and patient comfort is maximised.

Patient outcomes are frequently used as a measurement of the effectiveness of health interventions. These outcomes may vary, but generally, studies of palliative care for patients with dementia focus on quality of life (comfort, dignity, autonomy); family care; cognition; and advance care planning [12] [13]. When these outcomes are not met, undesirable outcomes such as unplanned acute hospitalisation; uncontrolled pain; distress for patient and family; poor medication management; disruptive behaviour; and treatment that does not match patients' stated wishes or goals may result [14]. It is the aim of the palliative approach to ensure that unnecessary interventions be avoided and only those interventions which will enhance the patient's quality of life and ensure positive outcomes for the patient and her or his family are used.

The *Guidelines for a Palliative Approach in Residential Aged Care* recommend that a multidisciplinary approach be taken to palliative care [10]. One way in which personnel from a range of health disciplines can be included in a palliative approach is through case conferencing. Case conferencing has been defined by the Australian Government Department of Health and Ageing as “a meeting or discussion at which the patient’s usual GP and at least two other health and community care providers discuss a patient’s care needs and look for ways to better coordinate the services that the patient will be receiving” [15]. These other health and community care providers may be drawn from a variety of disciplines, including, but not limited to, nurses, social workers, allied health practitioners and pastoral care personnel [16]. Ideally any meaningful case conference would include the family and in particular the decision making members of the family, as differences in attitudes and beliefs between doctors, nurses and relatives can influence decision making [17]

The Commonwealth Government introduced an Enhanced Primary Care package in 1999 to improve coordination of care for older people, which included reimbursement of general practitioners for case conferencing. Case conferencing is seen as useful tool for planning and coordinating care for people with cognitive problems who are unable to coordinate their own care among providers [18]. Uptake of the Medicare item for case conferencing by GPs has been low, though it is increasing [19]. Reasons for the low uptake of these items by GPs have been investigated in several studies by Mitchell and colleagues [20, 21] and will be explored in this review. Generally, a lack of available time and low levels of reimbursement appeared as two of the most common barriers to the adoption of case-conferencing in general, which would be expected to also impact on the adoption of case-conferencing for palliative care [22].

GPs who participated in focus groups also identified timing as a factor which may impact on the effectiveness of case conferencing; that is, when and how often they are conducted [21]. Both GPs and palliative care specialists in one study found that holding case conferences at critical points in the patient’s illness (e.g. at admission, prior to discharge home, when there were a number of complex issues requiring clarification) were more useful than holding case conferences on a routine basis [20].

This review will investigate whether the palliative approach for people with dementia is an appropriate and effective model of care for people with advanced dementia and their families.

## **CRITERIA FOR CONSIDERING STUDIES FOR THIS REVIEW**

### **Types of participants**

The qualitative component of this review will consider publications that include people with advanced dementia who live in the community or in residential aged care facilities and their families.

The textual component of this review will consider studies that include people with advanced dementia who live in the community or in residential aged care facilities and their families.

The quantitative component of this review will consider studies that included people with advanced dementia who live in the community or in residential aged care facilities and/or their families.

### **Types of interventions**

The qualitative component of this review will consider studies that investigate the appropriateness of a palliative approach for people with advanced dementia and their families.

The textual component of this review will consider studies that describe a palliative approach for people with advanced dementia.

The quantitative component of the review will consider studies that evaluate the effectiveness of a palliative approach for people with advanced dementia.

### **Types of outcome measures**

This review will consider studies that include the following outcome measures:

- Effective pain management
- Symptom control
- Satisfaction with decision making
- Place of death
- Specialist palliative care team involved for consultation
- Antibiotic usage
- Usage of artificial hydration and nutrition
- Percutaneous endoscopic gastrostomy usage
- Advance Health Directive completed
- “Not for resuscitation” order completed
- “Living will” completed
- Advance expressions of wishes followed.
- Transfer to acute care
- Function (e.g. as measured by the Australian-modified Karnofsky Performance Status Scale [AKPS])
- Quality of life
- Satisfaction with pain management
- Infections (e.g. pneumonia, urinary tract infections)
- patient-defined goals
- hospital bed days
- after hour medication visits/calls
- emergency department attendance
- unplanned hospitalisation
- total resource utilisation
- problems raised during case conferencing
- care of the bereaved next of kin

### **Types of studies**

This review will consider studies that focus on qualitative data including, but not limited to, designs such as phenomenology, ground theory, ethnography, action research and feminist research.

In the absence of research studies, other text such as opinion papers and reports will be considered in a narrative summary.

The qualitative component of the review will consider interpretive studies that draw on the experiences of people with advanced dementia and their families, including, but not limited to, designs such as phenomenology, grounded theory and ethnography.\*The textual component of the review will consider expert opinion, discussion papers, position papers and other text

The quantitative component of the review will consider any randomised controlled trials; in the absence of RCTs other research designs, such as non-randomised controlled trials and before and after studies, will be considered for inclusion in a narrative summary to enable the identification of current best evidence regarding a palliative approach for people with advanced dementia.

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