



Australian and New Zealand Society for Geriatric Medicine

Position Statement 16

Palliative Care for the Older Person

2009

1) Australia has an increasing ageing population with more people dying at an older age. Older people are more likely to die of illnesses other than cancer, often with multiple medical co-morbidities requiring management. The dying trajectory is usually longer in an older person.

2) Palliative care is an approach that aims to optimise the quality of life of patients and their families facing the problems associated with life-threatening illness. It can be offered at any time after diagnosis of a life-threatening illness and integrated into an overall care plan. The Palliative approach can be practised by all clinicians, with assistance from specialised palliative care services when required.

3) Death is a topic that can be difficult to discuss, so patients and their families may not be well prepared. In particular non-malignant illnesses may not be recognised as life limiting but can have a worse prognosis than cancer.

4) Good communication with the patient and carers about the disease and its' prognosis is the key to delivering good palliative care. Discussions should be with the competent older patient, with family involved at the patient's discretion. When incapacity is present a surrogate decision maker may need to be involved, depending on the laws of each state.

5) Older patients need advance care planning. Realistic treatment goals should be established based on likely outcomes that would be acceptable to the patient. Clinicians can then select what medical interventions may be appropriate on this basis. At times of change in medical condition a review of these choices may be required. Older patients should be aware of their right to cease active treatment of medical problems to concentrate on palliative goals, emphasising that comfort care will always be provided.

6) Dementia is a common condition of the older person that requires particular attention. It generally has a prolonged course from the time of diagnosis, and physical function is often maintained despite loss of higher brain function. Comprehensive management of dementia should include early future planning due to the potential loss of decision making capacity. Advanced dementia should be recognised and managed supportively as a terminal illness. It needs to be recognised that these patients are at high risk of uncontrolled symptoms, in particular pain.

7) Location is an important aspect of care in the dying older person. Familiar environments are preferred, especially for cognitively impaired patients. Effective advance care planning avoids unwanted transfers to hospital. Residential care facilities (RCF) commonly provide end of life care for older people. Palliative Care in RCF is supported by the Guidelines for a Palliative Approach in Residential Aged Care. Effective communication between hospitals, residential care providers and community teams about a patient's wishes is essential.

8) End of life care of the older person is ideally provided by a multidisciplinary team, to help address physical, psychological, social and spiritual issues. Older persons need comprehensive assessment for symptoms related to their co-morbidities and specific to dying. These require methods and tools that are sensitive to culture and validated for cognitive impairment when appropriate.

10) Common symptoms that respond well to medication are pain and dyspnoea. Medication should be prescribed for regular dosing intervals, with intermittent additional boluses as required.

11) Disease modifying treatments such as chemotherapy may be useful to manage symptoms and should not be discounted based on

age alone. Disease specific medications, e.g. for heart failure, should be continued when they are providing symptom relief. Medications prescribed only for disease prevention and whose side effects now outweigh benefit should be ceased.

12) Psychological and spiritual issues at end of life should be identified and addressed. Common concerns of the older person include loss of control, independence and dignity, impaired cognition, and the fear of becoming a burden to their family.

13) Clinicians need to be able to recognise the terminal phase of illness. This can be difficult, but should be attempted as it provides more effective end of life care when treating teams are concordant. Clinical indicators can include loss of cognition, recent hospitalisations and decreasing functional status. In some situations, investigations may be required to improve accuracy of prognostication.

15) Carers and families need support during the dying process of older patients. In particular, carers of patients with dementia may experience anticipatory grief prior to actual death. Grief is an important issue for all families after a loved one dies of any condition. The experience of the death can have a significant impact on carers. During the terminal stages, carers should be assessed for risk of complicated grief. Information about bereavement services should be routinely provided.

16) Improved education in palliative care is needed at all levels of medical training, by teaching and by example from senior clinicians. Advanced Trainees in Aged Care should be encouraged to undertake training in palliative care.

17) There is a need for increased funding for community services and specialised equipment to facilitate keeping dying older people at home or their preferred location.

18) Research needs to continue into the optimal management of the dying older person. This should focus on end of life needs and service utilisation of older adults. The benefit of palliative care approaches in cancer needs to be confirmed in those patients with non-cancer illnesses. In particular, the unique needs of patients dying with advanced dementia need to be addressed.

This position statement represents the views of the Australian and New Zealand Society for Geriatric Medicine. This paper was written by Dr Jonathan Marriott and Dr Juli Moran and was approved by the Federal Council of the ANZSGM on 3 June 2009.

BACKGROUND PAPER

Introduction

Australia has an increasing ageing population with more people dying at an older age [1]. Older people tend to have multiple medical comorbidities, and can suffer lengthy periods of functional decline prior to their death [2,3]. They are more likely to die of illnesses other than cancer, and often do not receive appropriate end of life care [3].

Palliative care is an approach that aims to optimise the quality of life and dignity of dying patients [4]. The World Health Organisation definition of palliative care states that it “offers a support system to help patients live as actively as possible until death, to help the family cope during the patient’s illness and in their own bereavement” [5]. However, palliative care services have traditionally focussed on deaths from cancer, which is less applicable to older patients [6]. Optimal care of the dying older patient requires an approach that is more understanding of their specific needs [7].

Prognosis and Illness trajectory in Elderly patients

The relative frequency of cancer as a cause of death decreases with advancing age, with coronary disease the major cause in non-institutionalised elderly [8]. The older person often suffers from multiple illnesses that contribute to the dying process and the terminal phase of care can be prolonged [9].

The difficulty in assessing prognosis in non-cancer illnesses has been one of the major barriers to implementing palliative care. This affects planning for both the individual and services [10]. Studies aimed at identifying prognostic markers in the older person have found that increasing falls and declining functional state, communication and ability to perform personal care are all associated with increased mortality [10]. However these predictors are non-specific and could be consistent with delirium or depression. It is acknowledged that models used to predict survival time are limited in accuracy and precision [11].

An understanding of common illness trajectories in the older person can assist with educating patients and families and planning appropriate care. Three disease patterns have been identified [6]:

- 1) Cancer: A period of functional stability after the time of diagnosis, ending with a rapid and predictable decline over weeks to months, making it easier to institute traditional palliative care services.

- 2) Organ failure: Chronic conditions such as congestive cardiac failure or airways disease tend to be characterised by recurrent exacerbations with loss of function, which may return to baseline. Symptoms can be burdensome over a long time, while death usually results from an acute exacerbation.
- 3) Frailty: Many elderly experience progressive disability. An increasing number of medical and geriatric conditions often lead to a failure of multiple body systems, and increasing frailty over years [3]. The insult that leads to death itself may be relatively minor and unpredictable.

One obstacle to effective end of life care in the older person has been termed “prognostic paralysis” [10]. This is when doctors feel unable to determine prognosis and therefore do not discuss the possibility of dying. Doctors may also be reluctant to diagnose dying if any hope of improvement exists, which is difficult to predict in chronic disease [12].

It is important that doctors become skilled in recognising the terminal phase of life. If impending death is not diagnosed it can lead to a loss of trust, conflicting messages, uncontrolled symptoms, inappropriate medical interventions and a failure to meet spiritual and cultural needs of patients and family [12]. Team members should agree when the patient is most likely in the terminal stages of life and communicate a consistent message to relatives [12].

Due to the difficulties of predicting prognosis, care of the older person should integrate active and palliative management [6]. The World Health Organisation definition of palliative care was updated in 2004 to encourage this approach [13]. Therefore the medical care of persons with chronic illnesses punctuated with reversible exacerbations should include ongoing symptom management. Palliative measures gradually take precedence over life prolonging efforts when death seems more likely [6].

Communication

Good communication is the key to effective palliative care and begins with discussing goals of care. Listening and providing information have been shown to decrease anxiety and increase family satisfaction in the palliative care setting, including for patients with dementia [14, 15]. Conversely, interviews with bereaved relatives have shown that communication failure was the usual problem when care was perceived as inadequate [16].

In any discussion, clinicians should engage the competent patient first and involve family if the patient chooses [17]. An open patient-centred interview is associated with an improved level of satisfaction for patients and their families [14]. Practitioners should aim to educate in a clear and positive fashion to ensure that informed decisions can be made [18]. Information provided should cover prognosis and the possible course of the disease. It is important to explain that palliative care is not cessation of active treatment, but simply a change in direction of care [18].

Patients often welcome the opportunity to discuss their impending death and expect their doctor to initiate these discussions. However, clinicians should remember that not all older patients will necessarily have considered this issue previously [19].

Planning

Once the patient has been given adequate information about their disease and prognosis, it is important to discuss treatment goals and limitations. This is because many patients are unable to make decisions about their care at the time of illness due to conditions such as dementia and delirium [3]. Family members or agents are then expected to act as decision makers. Unfortunately, research has shown that there is a low rate of concordance between patient preferences and decision-making by family or physicians [2,20,21]. There is a strong tendency for families to select more aggressive care than that which the patient would want [20]. Therefore patients should be encouraged to discuss their treatment goals with family and doctors whilst they retain decision-making capacity.

A discussion of medical goals should include potential limitations of future treatment. This often centres initially on cardiopulmonary resuscitation and admission to intensive care units but can extend to other interventions. Many patients and family, even in this informed age, may not understand the complexities of treatment options and outcomes in the care of older patients and will need specialist guidance and explanation [19]. This means that it may be more relevant to concentrate on functional outcomes that are acceptable to patient and family with medical staff giving advice about the appropriateness of complex medical interventions. Futile treatment interventions should not be offered. Usually there will be a need for patients, family and clinicians to meet after changes in medical condition to ensure the goals are still appropriate [22].

The notion of a “good death” is one that is free from distress and suffering for patients and caregivers [23]. Whilst there are parameters beyond the control of a clinician or patient, there

are elements that the patient and family can plan [24]. Such issues include location of care [see below] and goals of future medical treatment. Concerns that are consistently raised by older people in research are their desire to have pain and other symptoms relieved, and an optimal quality of life [14]. To this end, avoidance of being a burden to families, having a closer relationship with loved ones and maintaining a sense of control are paramount [14,25].

One form of recording wishes is the use of advance directives. Their use in Australia is not yet standard practice and debate still surrounds their role [17]. Some of the perceived limitations of advance directives include their inability to describe all the situations that might be confronted by the patient and their inflexibility in this regard [26]. Another recognised concern is that discussing advance planning with patients could cause adverse emotional effects [27]. Their scope appears to be more applicable to the terminally ill [26]. Programs that are well coordinated and provide good education and documentation can increase utilisation [26].

Location and Care providers

Location of end of life care has an impact on the quality of life of the patient and also that of the caregiver [7, 27]. This is influenced by demographic factors, diagnosis and health resources [27]. Studies reveal that most people want to die at home but this often does not occur [6,7, 27]. Familiar environments such as residential care or the home are preferred for patients with cognitive impairment [28].

There are many factors required to keep someone at their home for end of life care, especially good planning and skilled care [7,29]. Palliative care services have been shown to improve pain management and reduce the likelihood for hospitalisation of older patients [10]. Unfortunately, it has also been shown that older cancer patients are less likely to be referred to specialist palliative care services [7].

Patients with non-malignant conditions, especially dementia, are often not admitted to palliative care units for a number of reasons [4,5,30]. Carers may be unaware of hospice as an option, dementia may not be recognised as a terminal illness or the potentially long prognosis may discourage hospices from accepting a patient [31]. In addition, palliative care staff feel that they lack the necessary geriatric skills to manage illnesses such as dementia, especially with behavioural problems [31]. This often means that patients die in acute hospitals, which can often be the setting of death by default rather than patient choice [10]. This is unfortunate, given that the transfer to hospital of older patients [especially with cognitive

deficits] is often associated with multiple adverse outcomes [32].

Due to the chronic nature of many non-malignant illnesses, functional decline means that many people are now dying in residential care facilities [RCF]. These have been the focus over previous years of intense research and education to improve the provision of palliative care. Most significant has been the development of evidence based Australian guidelines for the provision of palliative care in residential care facilities [33].

If an older patient is transferred to a hospice or hospital the receiving staff should be respectful of the important role of carers who may have been involved with the patient for a number of years [11]. Support should be provided to carers, who may experience significant guilt at relinquishing care and ongoing involvement should be encouraged [4]. Relatives should be kept informed of the patient's current condition and the natural course of the disease, including the expected outcome of intercurrent illnesses. Good communication with families, including goal setting, will mean that unnecessary transfers between facilities can be avoided [32,34].

Assessment & Symptom Control

There are many similarities between assessment and management by palliative and geriatric units. Good palliative care of the older person begins with a comprehensive multidisciplinary assessment. Domains that should be assessed include physical, psychosocial, and spiritual. It is important to set goals relevant to the patient's current presentation [14]. Discussion should concentrate on issues such as prolongation of life, functional maintenance and comfort. Ongoing review of medications should occur, with cessation of medications with side effects that now outweigh the benefit of disease prevention [35].

Dying at any age can be preceded by unpleasant symptoms, but in the older person these are usually present for longer [36]. Symptom management can be complicated by a number of different factors. Disease burden is greater with common geriatric conditions such as delirium, incontinence, and sensory deficits requiring attention in conjunction with common terminal symptoms, such as pain, nausea and shortness of breath [36]. Potentially reversible conditions should be sought and treated with the aim of reducing symptom burden [37].

Pain in the older person can be the consequence of a number of different conditions [38]. Dying with pain is a major concern for older patients, yet it is under-recognised and under-treated, especially in patients with dementia [38]. The use of regular

analgesia is more important in a population who may not be able to effectively communicate that they are in pain [38]. Pain tools that have been developed for use in patients with dementia should be used [39]. Concerns about opioids related to fear of addiction and hastening death can be allayed with good communication [27]. Attention to pain management is included in the residential care guidelines [33].

There may be occasions when disease modifying treatment is required for symptom control. Although most cancer trials tend to recruit younger patients, age itself is not a good predictor of a patient's life expectancy or ability to tolerate treatment [40]. Many well and independent older people are appropriate for treatment such as chemotherapy or radiotherapy, although dose reductions are often considered [40]. Many palliative treatments have a low side effect burden, and should be considered for symptom control. If in doubt, the opinion of an oncologist should be sought.

The older person has often experienced cumulative loss over a lifetime and addressing spiritual and existential issues is an important component of end of life care that should not be neglected. Most older patients welcome enquiry about their spiritual well-being from their physicians [14].

Dementia as a terminal illness

Dementia is a terminal illness with no disease modifying treatment currently available [32]. It generally has a prolonged course from the time of diagnosis, and physical function is often maintained despite loss of higher brain function [41].

Comprehensive management of dementia should include early future planning [17, 42]. Discussions should begin as soon as possible after diagnosis, ideally with the completion of formal advance care plans and the appointment of a medical power of attorney or surrogate decision maker according to the law of each state [17]. People may define significant thresholds, such as when they no longer recognise loved ones, as a time to change the goals of their medical care [17].

Quality of life is an important measure that influences the setting of goals. It is difficult to assess in more advanced disease as it is a subjective issue [17]. It cannot be assumed that the person with dementia has a poor quality of life and it is important that the life of a person who has dementia is not devalued [43].

Every person with late stage dementia should be given good palliative care in order to prevent a painful and degrading death [25, 43]. It is

important to avoid therapeutic nihilism, as there is still much that can be done to alleviate symptoms and offer appropriate psychological and spiritual support. Dementia validated tools should be used for the assessment of symptoms [39].

The burden of therapeutic interventions in patients with advanced dementia is larger than the burden in cognitively intact individuals [32]. They are often unable to comprehend the need for interventions, and may perceive it as assault [32]. Antibiotic therapy may be warranted in many situations but clinicians should be aware that its effectiveness is limited by the recurrent nature of infections in advanced dementia [32]. Sometimes time-limited trials of interventions can provide more evidence of their merits to family [22]. Artificial feeding or provision of nutrition has not consistently been shown to have benefit, may cause unpleasant side effects [17, 32] and is not typically advised in advanced dementia [43, 44]. When treatment prolongs life without improving quality of life it should not be recommended [43]. Chance of recovery alone is not a sufficient reason to embark on a treatment course if the hazards are great and the patient has reached the terminal phase of their dementia illness [43].

Carers and families need ongoing education and support during the dying process. Dementia has the problem of 'ongoing losses'. Carers may suffer anticipatory grief, and it is important to identify those at risk of complicated grief after bereavement [45]. Staff trained in palliative care understand the importance of supporting families when the patient dies. It has been shown that follow up after death of patients with dementia is poorer than that of cancer patients [15]. This can be particularly important with carers of patients with dementia known to experience more guilt due to their inability to care for loved ones at home [15].

Training and Research

Improved education in palliative care is needed at all levels of medical training. It is currently only a minor part of the undergraduate training program and needs an increased commitment from medical schools. Physicians can improve care of dying patients by teaching students and junior doctors the knowledge and skills needed [18]. Increased competencies are important for the variety of different professionals involved in care of the dying elderly, including the need for improved communication skills. Advanced Trainees in Aged Care should be encouraged to undertake a minimum of six months training in palliative care, while palliative care services would also benefit from having Aged Care trainees. With the emphasis on palliative care being involved earlier in the course of disease, their

experience in functional maintenance will be useful when providing restorative care.

Raising awareness of palliative care for the older person is needed at state and federal government levels. Previous government initiatives include the National Palliative Care Strategy by the Department of Health and Ageing in 2000. This sought to define the priorities of palliative care in Australia, including that of older people and residential care. Subsequent development of national palliative care performance indicators by the Australian Institute of Health and Welfare looked at planning and delivery of palliative care services [46]. Whilst there is commitment by some state departments, e.g. the Victorian Strengthening Palliative Care policy [47], health care must adapt to the increasing number of older Australians dying of chronic non-malignant illnesses [48]. There is a need for increased funding for community services and specialised equipment to facilitate older people staying at home to die.

Research needs to continue into the optimal management of the dying older person. There is minimal evidence focussing on end of life needs and service utilisation of older adults [3] or on the palliative management of advanced dementia. Palliative care in non-cancer illnesses is recognised as an issue in the international literature, but again little has been done in Australia. Areas that could be targeted include the evidence base for symptom treatment, further evaluation of caregiver burden, understanding the patients psycho-spiritual well being and quality of life and adapting research methodologies to suit these [11]. It is important to validate assessment tools in this population, including in dementia. The values, attitudes and needs of the older population in relation to dying, death and bereavement need to be researched effectively.

Geriatricians are strongly committed to providing the best of care to older Australians, and have many of the skills and attitudes required to provide good palliative care. An awareness of the many issues involved in dying elderly and collaborative work with the Chapter of Palliative Medicine will ensure that the care of dying older Australians will continue to improve.

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