

Chapter 21 Palliative care

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Palliative care and the hospice movement were founded as a response to people dying from cancer^[1]. However, there is now wide recognition that palliative care should be provided and made available for people with a range of progressive advanced chronic diseases including dementia, frailty and organ failure. This is particularly pertinent as the population ages and a growing number of people are dying with these conditions. This chapter defines palliative care and the role of the psychiatrist, and examines some current issues in palliative care including: having difficult conversations, dealing with uncertainty, symptom control, and supporting grieving family and friends both before and after death, with a focus on the needs of those with dementia.

Defining palliative and end of life care

The World Health Organization defines palliative care as *“an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment*

and treatment of pain and other problems, physical, psychosocial and spiritual"^[2]. This definition recognises that palliative care is not only reserved for patients at the final stages of a progressive advanced chronic disease but for their families and throughout the disease trajectory. Palliative care, however, is distinguished from end of life care which typically focuses on the last 6-12 months of life and the dying phase. While palliative care encompasses end of life care, it is a broader concept encompassing the entire period of a life-threatening condition and conditions which may respond to treatment.

While specialist palliative care services focus are available, there is a growing need for a general palliative care approach across all care settings including primary care and general practitioners. This is particularly important as an increasing number of older people reside in long term care settings. However, those who remain in their own homes will require access to palliative care as family carers are often not equipped with the skills to manage pain and other symptoms.

Multidisciplinary care and the role of the psychiatrist

Using a palliative care approach, patients and their families should be cared for by a multidisciplinary team of health and social care practitioners who seek to relieve distressing symptoms and address psychological, social and spiritual needs. This is especially important for frail, older adults who are likely to have comorbidities and complex needs requiring support from psychiatry, geriatric medicine and palliative care. A multidisciplinary approach to palliative care is associated with reduced costs due to a reduction in hospital stays and carer satisfaction^[3].

Collaboration between palliative care and psychiatry has strengthened over recent years^[4], however, there is minimal research on the palliative care needs of people with severe, life-long mental health conditions^[5] except to suggest that they are less likely to access specialist palliative care compared to the general population^[6]. Psychiatrists can also support those with progressive advanced chronic diseases who experience psychiatric symptoms including depression, anxiety and delirium. Their input could improve the recognition and treatment of neuropsychological symptoms in particular in the management of delirium^[7].

Dementia is another area where support from old age psychiatrists is vital; from diagnosis through to end of life. Areas such as management of behavioural and psychological symptoms of dementia (BPSD) and their relationship with pain, advance care planning, complex grief reactions of family carers and assessing capacity may all be issues encountered by psychiatrists throughout the

trajectory of caring for someone with dementia. Yet despite high levels of psychiatric symptom burden amongst people with advanced dementia, very few have access to specialist psychiatric services who may help in managing these symptoms^[8].

Prognostication and uncertainty at the end of life

Research into illness trajectories suggest that not all conditions follow the same trajectory and several illness trajectories have been proposed^[9]. These include a predictable trajectory with a high level of functioning during the early stages of disease followed by a rapid decline in cancer, gradual deterioration with acute episodes with organ failure and an initial level of low functioning with a slow decline as seen in frailty and dementia^[10]. Not all conditions follow a conventional course of decline and anticipating needs early on is crucial when providing care for older ageing adults. A palliative approach provided throughout the disease trajectory, would remove the need to recognise when people are in the dying phase.

Difficulties in prognosis bring challenges and often people want an indication of how long they or their relative is likely to live. This can help people make decisions about how they want to live their life and can impact on what sort of medical treatment they want. The three trajectories identified above are all associated with challenges in prognosis. People with dementia are often frail, have many comorbidities and tend to experience a prolonged period of decline with many acute events^[11]. The uncertain and individual nature of dementia makes it not only difficult to plan for end of life, but also the diminished communication of the individual can create additional challenges for family carers and health care practitioners. Many family members and some health care practitioners do not perceive dementia to be a life-shortening condition, despite it becoming one of the most common reasons for death in developed countries^[12].

Advance care planning

Advance care planning has been defined as a *“process of discussion that usually takes place in anticipation of a future deterioration of a person’s condition, between that person and a care worker”*^[13]. It is important to note it is a *process* of conversations and communication between the person with a terminal condition, professionals and those close to the individual such as friends or family. This process gives patients and families an opportunity to think about what is important for them and to plan for their future care^[14].

There are multiple components to advance care planning, many of which are legally binding, for example in the UK, USA and the Netherlands, however this should be clarified in each respective country. Advance care plans include advance statements about what an individual would like to happen at the end of life, such as a wish to remain at home or even the type of music they would like to have played when they are in their final hours. An advance decision to refuse treatment may include a decision to not use antibiotics for a chest infection. Initial conversations can begin with broad topics including where the person would like to be cared for, before moving on to detailed discussion around treatments such as antibiotic use and Do Not Attempt Resuscitation. Practitioners should offer an opportunity for patients and family carers to discuss how a disease may progress and end of life care as they may not be aware that a condition is terminal or may assume that a health care professional will raise important conversations. For those with dementia it is important that these discussions occur early in the disease when they may still have capacity to make important decisions about their care^[15].

Decision making at the end of life

At the end of life, clinical decision-making can be a complex process mixed with uncertainty when knowledge, time and resources are limited^[16]. Decisions at the end of life are often medically focussed and cover sensitive topics including: hospitalisation, artificial nutrition and hydration, and discontinuation of treatment including medications.

Decision makers should consult the advance care plan if one has been developed, however many will reach the end of life without one. For patients with diminishing capacity who have not developed an advance care plan when they had capacity, end of life decisions are left to practitioners and family members. This decision making should be a shared approach based on the known wishes and best interests of the dying patient. It is important that practitioners provide information to families which is clear and communicated in a sensitive manner.

Health and social care practitioners, however, often lack confidence, with even the most experienced practitioners finding end of life care decisions and discussions difficult. These conversations require a high level of skill and experience, many practitioners fear engaging in these conversations with families and those close to the patient^[17], with some even overlooking the importance of ongoing discussions about end of life care^[18]. Many practitioners often rely on families to know the wishes of the individual, however studies have shown that families cannot always relay these with accuracy^[14].

Both practitioners and family carers may be conflicted regarding their own values, beliefs, ethos and cultural belonging which may disagree with guidelines or the recommendations and actions of others^[19]. This may also lead to external conflict between practitioners, or between practitioners and families when views differ.

The challenges in making decisions and the uncertainty that practitioners face at the end of life is well documented. As a response research has explored methods of managing uncertainty and approaching difficult decisions, in particular engaging with families. A recent toolkit of heuristics to assist practitioners with difficult decisions towards the end of life in dementia is one such example^[20]. The toolkit covers four topics; eating and swallowing difficulties, agitation and restlessness, stopping routine care and reviewing treatment and interventions at the end of life. The toolkit could be applied in various conditions at the end of life and not just with people with dementia.

Symptom Control

Older people at the end of life may experience a broad range of physical symptoms. Not all practitioners will be able to manage these symptoms and sometimes their key role is to advocate for the person and ensure they are referred to appropriate services. Good pain and symptom control requires consideration of four key areas: physical, psychological, social and spiritual wellbeing. If one area is neglected, managing other symptoms is more challenging and quality of life is decreased.

Pain

Pain is defined as “an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage”^[21]. This encompasses “nociceptive pain” which results from tissue damage and also pain caused by nervous system disease “neuropathic pain”. In palliative care it is important to consider other sources of pain or distress - a concept known as “total pain”. These include psychological distress (depression and anxiety) or existential distress - feelings of hopelessness, meaninglessness, or fear of dying.

Identifying pain and using pain scales

The cornerstone of managing pain in older people is comprehensive and detailed assessment. This can be challenging when older people have dementia, complex multi-morbidity, visual and hearing impairment. They may not be able to report or remember that they have been in pain. Self-report is

the “gold standard” and people with advanced dementia may be able to indicate that they are in pain. Observation and detailed history taking are also important.

Observational scales are helpful in people with cognitive impairment, communication difficulties or dementia. These include items mainly based on the AGS (American Geriatrics Society) Guidelines^[22] which include a range of indicators; facial expression, verbalization and vocalizations, body movements, changes in interpersonal interactions, changes in activity patterns or routines and mental status. Observational scales highlight how pain or discomfort may be expressed as behavioral change, for example agitation, distress, social withdrawal, depression, or resisting care^[23].

There is no “perfect” pain tool. Their main advantage is that they encourage practitioners to observe for changes and potential pain indicators from a range of domains. The most widely used and well validated pain tools include the Abbey Pain Scale and the Pain Assessment in Advanced Dementia (PAINAD)^[24].

Managing pain

A stepwise approach should be taken starting with non-pharmacological management, this includes massage, heat, cold, physiotherapy and repositioning. Topical preparations such as non-steroidal anti-inflammatory (NSAID) creams may be a helpful initial step for arthritic pain. The general principles of pain management are to start low with one drug at a time, avoid combination therapy and polypharmacy and titrate the dose slowly. Medication should be given regularly, *before* pain occurs; this is vital in people with cognitive impairment who may not remember they have been in pain or are unable to express this^[25,26]. Simple analgesics i.e. paracetamol should be the first line treatment. NSAIDs can be helpful but care is needed because of their renal, cardiac, and gastrointestinal side effects. If there is a lack of response, the next step is to move up the WHO pain relief ladder^[27] to weak opioids such as codeine and then stronger opioids such as morphine or fentanyl.

Opioids are relatively safe if carefully titrated and response monitored closely. Common side effects of weaker opioids include drowsiness and constipation. Stronger opioids such as fentanyl may suppress respiration and should not be started in opioid naïve patients. Common side effects are hallucinations, delirium, nausea, vomiting and urinary retention. Some stronger opioids are available as patches i.e. buprenorphine-helpful if patients cannot swallow. Specialist advice should be sought if escalating through the pain ladder.

It is important to consider possible specific causes of pain. Whilst pressure sores and arthritis are common in older people, particularly those with advanced dementia, a person may have lifelong conditions such as migraine, or chronic pain due to diabetic neuropathy. Neuropathic pain may require treatment with antidepressants (i.e. amitryptilline) or anticonvulsants (i.e. gabapentin)^[28]. Treating pain appropriately is worthwhile. A stepwise approach to prescribing analgesics reduced agitation and depression and improved sleep in care home residents with dementia^[29,30].

During the terminal phase of life, broadly the last 48 hours, people may become very distressed by pain and it may be appropriate to start opioids via syringe-driver. This has the advantage of rapid action and quick achievement of stable plasma levels. The use of syringe drivers is usually initiated by an experienced general practitioner or palliative care team.

Nutrition and hydration

Swallowing difficulties are common in people with dementia or those who have had strokes or other neurological problems. Over 50% of people with advanced dementia will have problems with eating or swallowing^[8] and survival rapidly decreases after the onset of these problems^[31]. The person may have lost awareness for what food is, may not be able to chew or may have lost their swallowing reflex and be at risk of aspiration and developing pneumonia. Enjoying eating and drinking are essential for maintaining quality of life and preparing and offering food is an important way to express care. Thus, when food is refused by a person with advanced dementia or they are unable to chew or swallow, it can be upsetting for families, friends and staff.

A Cochrane Review^[32] found inconclusive evidence that enteral tube feeding (nasogastric tube (NG) or percutaneous entero-gastrostomy (PEG)) increases survival time, decreases mortality risk, improves nutrition, or reduces the incidence of pressure ulcers in those with advanced dementia. There have been no studies on the effect of these interventions on quality of life. There are numerous adverse effects of tube feeding including increasing pulmonary secretions, incontinence and mortality. In addition, tube feeding removes the essential social interactions involved in eating, drinking and giving care.

Key considerations include whether “artificially” lengthening life in advanced dementia is ethical and whether not providing parenteral nutrition may constitute ‘euthanasia’ by hastening death. Just because there is little evidence for a benefit of tube feeding in advanced dementia may not mean it

is inappropriate. Each person should be assessed by a speech and language therapist and a dietician, family and close persons should be consulted and all appropriate interventions should be considered^[33]. The decision to use tube feeding may be influenced by, clinical need, local practice, physician and carer preference, and whether there is an advance directive or care plan in place.

The decision of whether to “feed or not to feed” is very dichotomous and absolute. However, there are alternatives to this binary approach. Modifying or thickening foods, using high calorie supplements, finger foods and offering alternative choices that the person likes by using personalised care documentation such as “this is me” may improve nutrition and increase weight^[34]. “Comfort feeding” is becoming more widely recognized as a useful concept in end-of-life care for people with advanced dementia^[35]. Here tastes and sips of food combined with mouth care are used to promote comfort, focussing on the quality of the interaction as much as the giving of nutrition.

Infections

Pneumonia and urinary tract infections, are common in advanced dementia. In the last 9 months, 13% of nursing home residents with advanced dementia will have a urinary tract infection and 20% pneumonia^[8]. People with advanced dementia have impaired immunological function, are immobile, bed bound and at increased risk of aspiration but the use of antibiotics to treat fevers and recurrent infections towards the end of life is controversial. van der Steen *et al.*^[36] found people with advanced dementia treated with antibiotics survived for longer (27% died compared to 90% of those who did not have antibiotics), however, this may have occurred because antibiotics were withheld from patients whom physicians believed had more severe dementia. Some research suggests withholding antibiotics increases the level of discomfort^[37], but they may also delay death, leaving the patient suffering and prolonging the dying phase. If antibiotics provide symptomatic relief i.e. for a painful urinary tract infection they may be in the person’s best interests. Again, careful and sensitive discussions with families and, if available knowledge of prior wishes should be used to guide decision making.

Breathing difficulties

Dyspnoea is a subjective feeling of having difficulty in breathing. In people with advanced dementia it is often a primary symptom affecting up to half of people in the 9 months prior to death^[8] but may be due to secondary causes such as chronic lung disease or cardiac failure. Dyspnoea can be frightening for people with dementia and their families and interventions such as relaxation and help with clearing secretions can be helpful. Referral to a physiotherapist may improve comfort. If these are not

effective, specialist palliative care advice should be sought. Oxygen is only usually necessary if the person is hypoxic. Drugs may be helpful, principally opioids and benzodiazepines^[38,39], but there is little good quality evidence for this. “Death rattle” is noisy breathing caused by respiratory secretions which pool and cannot be cleared. This may be distressing for the family both at the time and many years later. There is little evidence available on how best to manage this. Repositioning, suctioning and explaining to the family that the dying person is unlikely to be aware of this symptom are the main forms of treatment^[40].

Dealing with loss and grief

Grief is a normal emotional reaction to the death of a loved one. It is one of few affective states that is defined by its cause rather than its manifestations which can vary widely over time and culture. Most people will cope with bereavement through support from friends and family with information about bereavement and support services. A smaller number of bereaved people are potentially ‘at risk’ and may need additional support such as peer support groups and around ten percent are at risk of complex grief issues and may need more formal therapy from a health practitioner^[41]. Providing support to the larger population who are coping with grief through their natural support network could be considered more harmful than useful. This guidance, however, was developed in cancer services and may not be applicable for other common chronic and terminal conditions.

Persistent Complex Bereavement Disorder

There is a continued debate about the smaller ‘10%’ who experience intensive levels of grief over a longer period of time and which can substantially impact on daily life and functioning and whether this should be considered a mental health disorder. ‘Persistent Complex Bereavement Disorder’ has been posited as a disorder for inclusion in the Diagnostic and Statistical Manual of Mental Disorders, but in the fifth edition it was included as a condition for further study, indicating that more evidence was required. Features of this disorder include intense sorrow and persistent yearning and preoccupation for the deceased and circumstances of death. These symptoms occur more days than not and to a clinically significant degree for at least 6-12 months. This reaction would be considered out of proportion or inconsistent with cultural, religious or age-appropriate norms.

Grief before death while caring for a dying family member

One of the defining features of Persistent Complex Bereavement Disorder is that it has to occur as a reaction to someone’s death. Many frail older people and people with chronic and terminal conditions rely on the support provided by family and friends. The multiple losses that family carers

experience during long term care of people with chronic health conditions can trigger grief reactions. Personal losses can include reduced employment and finances, contact with other family and friends and loss of identity as the carer becomes focused on the wellbeing of the person they are caring for. Cognitive impairment can lead friends and family to feel their relative is no longer the same person. Adult children may describe role reversal where they feel their parent is now dependent on them. Partners and spouses may miss no longer being able to share decision making and feel they have lost their previous relationship. Between 47-71% of carers of people with dementia experience grief before the death and 20% experience the more persistent complex bereavement after death^[42]. Transition to a residential care or nursing home setting may also be another loss that can trigger grief.

These findings indicate that grief and emotional support during care rather than solely after death may be beneficial. For some carers the death of the terminally ill person may come as a relief. This may be due to no longer having to observe the decline and suffering of their relative or no longer having to be committed to a caring role. However, the caring role can also become a critical part of someone's identity and losing this role can also lead to feelings of despair and loss.

Feeling prepared for someone's death is negatively associated with Persistent Complex Bereavement Disorder^[43] and therefore helping people prepare for death may be a promising avenue for research. Preparation for end of life has medical, psychosocial, spiritual and practical components. Good communication with healthcare providers to discuss prognosis, treatments, cultural, spiritual and practical issues; and dealing with family conflict is important^[44], however, as discussed above, there are many obstacles to engaging in discussions about end of life care.

Two intensive interventions have been trialled with family carers of people with dementia to help manage grief. Paun et al^[45] examined 12 group sessions incorporating education about the progression of dementia and development of communication skills, conflict resolution and chronic grief management. Although they measured many outcomes, only heartfelt sadness and longing was significantly reduced in the intervention group. Meichsner and colleagues^[46] in Germany trialed 12 cognitive behaviour therapy sessions over 6 months with the intervention leading to reductions in carer grief. Analysis of the therapy sessions identified four key strategies used by therapists to address grief. These included: recognising and accepting loss and change, addressing future losses through awareness that dementia was terminal, normalising grief, and redefining the relationship^[46].

Interventions that help carers to acknowledge and accept their grief are promising strategies for supporting carers towards the end of life.

Conclusion

Palliative care offers an holistic approach to care that fosters quality of life and comfort through multidisciplinary input for older people with chronic and terminal conditions. Psychiatrists play a key role in supporting palliative care through their role in advance care planning, difficult conversations, symptom control and supporting grieving family and friends both before and after death.

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