

Long-term care in dementia – priorities and personalised approach

Introduction

Treatment and care of patients with dementia is associated with a range of ethical concerns, from the appropriate time for initial assessment to end-of-life issues. With the decline in mental capacity and independent functioning typical of this disease, self-determination becomes harder to achieve and patient representatives are increasingly involved in decision-making. Nonetheless, many patients, even in advanced dementia, can reliably express their wishes about decisions directly affecting them. It is an ethical priority that health professionals enable patients, as far as possible, to live according to their values and remain active in decision-making.¹ The broad professional consensus is that treatment and care are best guided by principles and goals similar to those of palliative care: improving quality of life; maintaining function and maximising comfort; interprofessional collaboration; open communication; supporting decision-making processes; and involvement of the patient's family.^{2,3}

LEARNING OBJECTIVES

You will learn:

- The importance of minimising the impact of dementia-related disability through available care methods
- To identify ethical considerations specific to stage of disease progression, from initial assessment to end-of-life choices
- The ethical considerations of changes to care and treatment goals in accordance with progression of dementia and related disability.



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Dementia: definition and stages of disease

Dementia is a syndrome characterised by memory and communication deficits, neuropsychiatric and behavioural disturbances and gradual loss of control over physical functions, which collectively indicate progressive brain damage. There are various causes, of which Alzheimer’s disease and vascular dementia are the most common. Prevalence rises with age, especially after 65; by 85, dementia affects about one in five people.⁴

Despite the profound cognitive losses, evidence suggests that some abilities and emotions are retained long into the

disease course: this challenges the view of dementia as a ‘death that leaves the body behind’.⁴

Current treatments are only temporarily effective, making it especially important that health professionals examine how best to support patients and minimise the impact of disability by making full use of available care methods.⁴ Dementia proceeds through stages according to how severely daily activities are impaired. Each stage raises specific ethical issues, with care and treatment goals changing over time (Figure 1).

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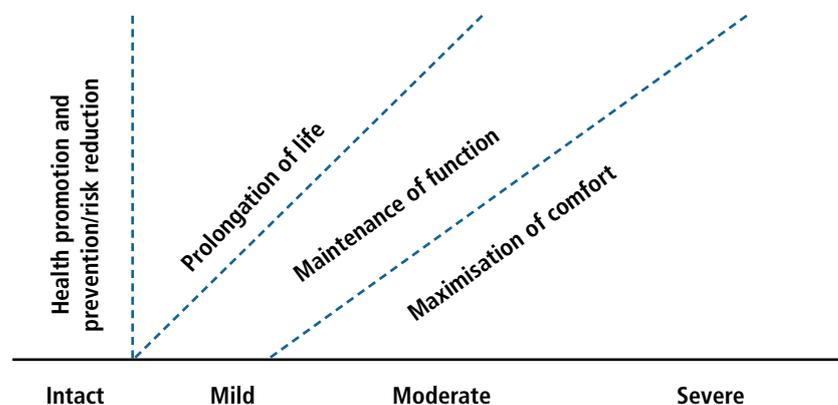


Figure 1: Dementia progression and prioritising of care goals

More than one care goal may apply simultaneously, e.g. in moderate dementia, maximising comfort, maintaining function and prolonging life all apply; but the first two may be increasingly prioritised over the latter. Adapted from Van der Steen, *et al.*³

In early-stage dementia, cognitive impairment is mild. The focus is on helping the patient and family adapt to the new situation, and providing support and planning for ongoing independent living. Ethical issues at this stage relate to appropriate timing of assessment and empathetic diagnostic disclosure. Advance directives should be drawn up at this stage.⁵

In mid-stage or moderate dementia, the patient struggles increasingly to perform daily living activities and needs more professional support, such as a care service. Interventions that are commonly

employed include adjusting the patient’s environment and daily routines, psychotropic drugs or measures restricting freedom of movement. The patient may need to move to a care institution.⁴

In late-stage, severe dementia, the patient typically has minimal verbal communication, often cannot recognise relatives and requires assistance in most areas of daily living. The focus is on comfort and end-of-life care issues, such as as possible withholding of life-extension measures.^{5,6}

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Ethical principles of care

Ethical decisions in dementia care should be guided by the principles of improving quality of life, respect for dignity and supporting self-determination or autonomy. As dementia progresses and the patient incrementally loses control over his/her life, quality of life depends increasingly on quality of care. High-quality care is informed by patients' habits and preferences, and is adapted to their abilities. It aims to ensure retention of independence and participation in social and cultural activities for as long as possible.⁴

Respect for dignity is intrinsic to each person's life, regardless of physical or mental disabilities. Ensuring patient dignity includes recognising him/her as a unique individual from a specific cultural background to be regarded with respect and empathy, and acknowledging his/her intrinsic value as a human being.²

Patients should be supported in self-determination, for example regarding treatment choices. In early-stage dementia, the capacity for self-determination is likely to be present, but erodes along with cognitive decline. In late-stage disease,

autonomy is respected by encouraging participatory behaviour through observing the patient's non-verbal expression of preferences, for example with regard to food choices. Participatory behaviour helps maintain functioning, ensures that individual needs are considered and lets patients experience self-efficacy.²

Communication in dementia care is challenging, given the impairments in cognitive abilities and speech; facial expressions and gestures are also often less pronounced. Caregivers should speak clearly in simple sentences while maintaining eye contact. Patients who can no longer communicate verbally generally perceive and appreciate non-verbal expression from carers (e.g. smiling, gestures, gentle touch).²

Capacity is assessed according to the specific decision. A patient may have lost the capacity for complex decision-making, but retain capacity for simple matters (e.g. dietary preferences). Where capacity is lacking, wishes and values nonetheless remain centrally important.²

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Decision-making processes

Medical interventions require a medical indication and the patient's informed consent. Advance care planning (ACP), which is then adapted to the actual disease trajectory, ascertains the patient's wishes and values, which will definitively guide care before capacity becomes limited. Physicians should encourage ACP to be done early on, as patient capacity is a prerequisite for this process. If the patient lacks capacity and no advance directive is available, the physician, in consultation with legally authorised representatives or relatives, formulates a treatment plan. This is guided by the patient's presumed wishes or, if these cannot be determined, his/her best interests.²

It should be noted that the right to refuse therapeutic interventions in ACP

does not extend to all care measures. For example, it cannot stipulate that, in severe dementia, essential care measures such as protection from cold be discontinued so as to hasten death.² Particularly in severe dementia, treatment and care measures often require interprofessional decision-making within the treatment and care team, before these are proposed to a patient or representative. Family knowledge also helps professionals to understand the patient's behaviour and identify needs in care planning throughout the disease course.⁴

The following section examines how the aforementioned ethical principles and decision-making processes are applied in various areas of dementia treatment and care.

Diagnosis of dementia

The quandary when deciding when to conduct dementia assessment is that, while early diagnosis is generally thought to be advantageous, it can also cause distress. Furthermore, current treatments, even if employed early on, do not significantly change the course of the disease.

Screening may put people through unnecessary stress for an uncertain outcome. Modest memory loss or mild cognitive impairment (MCI) increases the risk of dementia, but many people with MCI do not develop dementia, or only do so after several years. Genetic screening for Alzheimer's is controversial because a positive result cannot definitively determine that the disease will occur. Gene tests can accurately predict familial early-onset Alzheimer's disease, but this condition is rare.⁷

Nonetheless, early diagnosis and therapy can improve quality of life, allows for timely establishment of support measures and future planning, and delays the need for care. Where MCI is detected, preventive measures such as regular exercise can help slow the potential onset of dementia.⁶

Assessment is indicated if the patient or relatives voice concern about cognitive, psychological or behavioural disturbances, especially if these affect the person's normal daily functioning or risk

endangering him/her through activities such as driving.⁷

In addition to a medical history and physical examination, an informant history provided by a close contact is required to help the physician gauge functional impairment of daily living activities related to cognition. This is followed by cognitive testing and, if brain function impairment is suspected, imaging procedures (MRI or PET).⁷

If a patient with capacity refuses assessment, this should be respected. However, anosognosia (being unaware of or denying one is ill) is common in dementia, and if relatives request diagnosis, their concern should also be addressed. Discussion with all concerned may help in persuading the patient to undergo assessment.²

Preferably, a relative should accompany the patient to receive the diagnosis, but the physician should address the patient directly. Disclosure is likely to elicit distressing emotions, which must receive adequate attention: fears about loss of the self and becoming dependent are common. Empathetic disclosure, with assurance of continued support and information on coping, can help assuage such fears. Patients who are aware of their cognitive decline may become clinically depressed, even suicidal, and this must be identified and treated.²

Issues in care and treatment

Coercive measures

Patients can pose a danger to themselves and others through confusion, falls and behavioural disturbances such as wandering or aggression. To ensure their safety or to provide medical care, coercive measures, including restricting freedom of movement and sedative or antipsychotic medications, may be used. However, coercive measures represent an infringement

of personal rights and should never be used, for example, merely to make caregiving work easier. Where coercive measures are deemed necessary, they must be justified and regularly evaluated according to professional standards. The patient's representative must consent to the use of coercive measures, except in the case of an emergency.⁸

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Benevolent deception

People with dementia are vulnerable to manipulation through deception and there is a risk of their being exploited for personal advantage by relatives or professionals. Nonetheless, allowing a patient's objectively false statements to go uncorrected, or even active deception, may be justified where the motives for this are benevolent. The caregiver seeks to comprehend the patient's subjective perception and guide interactions to minimise conflicts between the real world and the patient's world.² For example, where an elderly patient believes their parents to still be alive, continual correction of this may only cause distress and be at odds with the goals of improved quality of life and care.

A related ethical issue is whether it is morally acceptable to use objects that simulate reality (e.g. dolls, robot pets, fake bus-stop signs) in dementia care. Proponents argue that patients appreciate such elements and incorporate them into

their perception of reality; that the intention is not to mislead but to elicit positive emotions. Such elements must not replace human care, however, but facilitate the caregiver-patient interaction.²

Medication is sometimes hidden in food when patients with dysphagia are averse to swallowing tablets. This facilitates administration and is generally ethically unproblematic. However, concealing medication that would otherwise be specifically refused by the patient can be seen as benevolent deception that is also coercive. This is only acceptable if drugs are urgently required and other less intrusive methods have failed.² It should also be noted that research indicates that several medications commonly given to patients with advanced dementia are of questionable benefit and have negative side effects. Physicians should consider the main goal of care at this terminal disease stage – comfort – when prescribing medication.⁹

Support for relatives

The patient's family often provides support and caregiving over several years, a role that carries significant physical, psychological and financial burdens. In addition, relatives must manage the role of proxy decision-maker in more advanced dementia, and frequently deal with prolonged grief and loss caused by the progressive deterioration of the patient. The high burden of care can become so overwhelming that caregivers risk falling ill themselves. In some cases, the resultant stress can even lead to abuse of the patient, especially if neuropsychiatric and behavioural symptoms are present.

Therefore, support for relatives is crucial in professional dementia care, for example through counselling services and advocacy groups. This, in turn, often reduces emotional and behavioural disturbances in the patient.³

People with dementia are particularly vulnerable to abuse, not only by relatives but sometimes by professional caregivers too, which can involve physical or psychological violence, neglect or exploitation. Physicians can use tools such as the Elder Abuse Suspicion Index (Table 1) to gauge the presence of abuse.¹⁰

Table 1: Elder Abuse Suspicion Index

Question 1-5 asked of patient; Question 6 asked of doctor. Questions refer to the past 12 months.		
Q1: Have you relied on anyone for bathing, dressing, shopping, banking or meals?	YES	NO
Q2: Has anyone prevented you from getting food, clothes, medication or medical care, glasses or hearing aid, or from being with people you wanted to be with?	YES	NO
Q3: Has anyone spoken to you in a way that made you feel shamed or threatened?	YES	NO
Q4: Has anyone tried to force you to sign papers or use your money against your will?	YES	NO
Q5: Has anyone made you feel afraid, touched you in ways you did not want, or hurt you?	YES	NO
Q6: Elder abuse may be associated with poor eye contact, withdrawn nature, malnourishment, poor hygiene, cuts, bruises, inappropriate clothing and poor medication compliance. Did you notice any of these?	YES	NO

Adapted from Yaffe *et al*, 2014.¹⁰

Managing delirium and pain

Dementia raises the risk of delirium, an acute, usually reversible, confusional state. Coercive measures can exacerbate delirium and are to be avoided. Medicines may be used judiciously - to treat agitation, for example. Relatives should be instructed on how to approach and communicate with the delirious patient, e.g. short sentences; yes/no questions. Underlying causes of delirium should be investigated: this may reveal treatable infections (e.g. urinary tract) or metabolic disturbances. Preventive measures include maintaining

a calm, stable, comprehensible environment, which includes avoiding rapid turnover of care personnel, as well as managing basic physical aspects of care, including nutrition, hydration and pain.² Pain frequently goes undiagnosed and undertreated in dementia. For pain assessment, the patient is asked to give a self-rating. If patients cannot indicate pain, systematic observation may help detect pain-induced behavioural changes. If pain is suspected, analgesics can be given while observing if behavioural symptoms improve.²

Comorbidity

Dementia often co-occurs with other chronic somatic and/or mental disorders. Treatments for the different conditions must be carefully considered to avoid the adverse effects of overmedication and drug interactions. Decisions about therapies aimed at improving the general prognosis, without directly improving

function or comfort, should be carefully weighed on an individual basis. The stage of dementia must be taken into account as well. For example, while controlling cardiovascular risk factors is also important for primary dementia prevention, it is unlikely that such measures are beneficial in advanced dementia.^{3,4}

Involuntary committal

Early-stage dementia patients usually live in their familiar home environment. As the disease progresses, moving into a care institution may become appropriate. This is straightforward if the patient agrees and has the capacity to conclude a care agreement. If capacity is lacking,

and a placement is medically indicated, the care agreement can be concluded by the patient’s representative. If the patient refuses such a move, they can be involuntarily committed, but only if treatment or care cannot be otherwise provided.²

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Withholding life-extending measures

Withholding life-extending measures in late-stage dementia is guided by patient wishes and their objective best interests. This does not imply reduction in care, but a greater emphasis on symptom alleviation. If comorbid diseases are present, then there are likely to be several potential treatment-withholding options. For example, with concomitant heart disease, cardiac surgery may be decided against. Without significant comorbidity, options for withholding life-extending measures are generally restricted to common complications of late-stage dementia, such as infections or poor food intake. If patients contract pneumonia, for example, antibiotics and hospitalisation may be decided against. Antibiotic therapy only extends life in a minority of patients, and it is doubtful that it significantly improves well-being.^{5,6}

If patients with advanced dementia eat little or stop eating, possible causes, such as oropharyngeal pathology, should be treated and the eating process assessed to detect cognitive factors (e.g. agnosia, where food is not recognised). Poor posture, as often occurs in bedridden or wheelchair-bound patients, may also impede intake. Dietary adjustments (e.g.

finger food) should be considered. Poor intake may be associated with a loss of the will to live, typically indicated by refusing offered food (e.g. turning the head away). This should be taken as an expression of wishes and the patient should not be forced to eat. Caretakers should continue to encourage eating by, for example, offering alternative foods at different times.⁴

Research shows that the use of a gastrostomy tube in advanced dementia does not significantly improve survival, and quality of life may be reduced by complications of the procedure. Use of artificial hydration must be determined by inter-professional discussion to weigh potential benefits (e.g. enhanced alertness) against risks (e.g. oedema).⁶

While dementia is a devastating diagnosis, putting in place an ethically sound treatment and care plan, one which adapts to the changing course of the disease, is a vital practical step which should be taken as early as is appropriate. It is invaluable for providing both patient and family with a sense of control and reassurance that all efforts will be made to protect their rights, dignity and self-determination according to their wishes.

KEY LEARNINGS

- Decline in cognitive ability and independent functioning raises ethical issues specific to the stage of dementia
- Treatment and care follow principles similar to those of palliative care
- In the earlier stages, the aim is to maintain functioning and support autonomy
- In late-stage disease, the focus shifts to maximising comfort and end-of-life care issues
- Early advance directives ensure that patient wishes guide care throughout the disease course
- Care methods that may infringe on patients' rights (e.g. coercive measures, benevolent deception) must be justified and regularly evaluated
- Support for relatives is an important aspect of professional dementia care
- Withholding life-extending measures in advanced dementia must be guided by patient wishes and their objective best interests.

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