

Advanced dementia

This summary highlights key messages from the research on advanced dementia.

Key messages

- Advanced dementia is characterised by severe cognitive and physical impairment.^{5,36}
- Understanding of the needs of individuals with advanced dementia is poor.^{8,36}
- The legal issues surrounding individuals with advanced dementia and decision-making are complex.^{8,10,12,13,14}
- Individuals with advanced dementia are likely to have other life-threatening illnesses.^{5,8} This has a huge impact on the costs of caring for people with advanced dementia.^{15,16,17,19}
- Caring for individuals with advanced dementia can be extremely challenging.^{19,20}
- As speech may not be available as a means of communication for people with advanced dementia, it becomes necessary to regard communication as something more than just talking.^{1,3,4,29}
- More research is required in terms of identifying ways of helping professional and family caregivers of people with advanced dementia to cope. This will involve accessing the experiences of carers and gaining knowledge from them.^{40,41}

Introduction

This summary highlights key messages from the research on advanced dementia. It is not intended to be a comprehensive review of the literature on this topic. The material was identified through focused searching of the literature published from 2009–2014 using the terms ‘advanced dementia’ and ‘severe dementia’. Some material pre-dating 2009 has also been referred to in order to illustrate matters of relevance, not contained within the retrieved material.

What is the issue?

People with advanced dementia may often be unable to communicate using speech and as such it may seem as though they are completely unreachable.¹ This can make it extremely difficult to assess how the individual with advanced dementia is feeling physically and mentally. Furthermore, it becomes increasingly difficult to measure the effectiveness of any interventions.² Indeed, the communication barrier experienced by individuals with advanced dementia has an impact on every area of the individual’s life, including social life, engagement in meaningful activities and quality of life.^{1,3,4} People with advanced dementia are more likely to experience other health problems than those with less severe impairment. This leads to a complex interaction of health issues that are both difficult to manage and assess.

Assessment

The classification and assessment of advanced dementia are both extremely difficult to define. The Global Deterioration Scale (GDS) describes the progression of dementia from stages 1 to 7. Although the progression of

the illness may be different for each individual, stage 7 of the GDS provides a useful description of the features of advanced dementia.⁵ These include profound memory problems, speech limited to fewer than five words, total dependence, incontinence and inability to walk.⁵ Over time, the condition worsens, eventually proving fatal. The estimated survival time from onset of dementia to death is 4.1 years for men and 4.6 years for women.⁶ People with advanced dementia are at high risk of developing other significant medical problems over the course of their illness, including pressure ulcers, pneumonia and swallowing difficulties.⁵ People with dementia who are admitted to hospital in emergencies have poorer outcomes in hospital and are at greater risk of dying compared to older people without a diagnosis of dementia.⁷

Legalities

There are many legal issues surrounding people with advanced dementia. These arise mainly because other individuals (that is, family members and guardians) have to make important decisions for them.⁸

Ethics

The range of ethical issues in the care of people with advanced dementia is far-reaching. It has significance in terms of involving people in research⁹, making staff training decisions, the development of clinical practice guidelines and the creation of plans for national strategies.¹⁰ The Nuffield Council on Bioethics produced a useful ethical framework designed to help those who care for people with dementia on a daily basis.¹¹ In terms of people with advanced dementia it has been argued that we should regard each individual as a ‘valuer’, that is, a

person capable of valuing. As such, we can receive information on how they value actions in terms of their facial expressions and emotions.¹¹

Decisions

We all have the right to make decisions about things that might affect our lives and this includes individuals with dementia. However, as the illness progresses to more advanced stages it becomes increasingly difficult to explain things and access the opinions of people with dementia.⁸ Making an advance decision, an advance statement or (referred to more broadly as) 'advance care planning', allows individuals to decide on important care that they may or may not wish to receive in the future should they at some point become unable to express themselves.^{12,13,14}

Cost

The costs associated with caring for people with advanced dementia are significant. Although there have been several advances in the diagnosis and treatment of people with advanced dementia, the future bill for long-term care could be huge and this implies uncertainty for people with dementia.¹⁵ In terms of funding, spending on research on dementia and stroke is severely underfunded compared to cancer and heart disease.¹⁶ When it comes to research on the cost-effectiveness of interventions to help people with advanced dementia, far more evidence exists on pharmacological therapies than psychological/behavioural interventions.¹⁷ Insufficient support and care of people with dementia often results in significant negative consequences for individuals with a diagnosis and high costs to the health and social care system.^{18,19}

Care

Caring for individuals with advanced dementia can be extremely challenging.^{19,20} Two-thirds of people with dementia live in their own homes and require support and care from spouses and other family members. However, research findings suggest that many people with dementia and their family caregivers have restricted access to the support and care they require – and this can have a negative impact on all concerned.¹⁹ A case study of a specialist advanced dementia service showed how this could be achieved by bringing together health and social care services to help people with dementia stay at home for as long as possible.²⁰

Technology

In 2004, The World Health Organization defined assistive technology as: '...an umbrella term for any device or system that allows individuals to perform tasks they would otherwise be unable to do or increases the ease and safety with which tasks can be performed.'²¹

Technology can have an important role to play in supporting people with advanced dementia and keeping them safe.²² For example, fall detectors, flood and smoke alarms may be used by at-home carers or care homes to keep people protected. Other types of sensor-based technology can gather information about the activity and health of the person with advanced dementia. This can help to identify an individual's needs as well as offer reassurance to family and friends.²³

Increasingly, assistive technology is being promoted as a way of offering tailored support for people with dementia. In 2014, the Dementia-Friendly Communities Champion

Group (one of three that are working to deliver the Prime Minister's Challenge on dementia) launched a 'Dementia-Friendly Technology Charter'.²⁴ The aims of the charter are to help people with dementia to benefit from technology that is appropriate to their individual needs, and to outline and encourage the implementation of high-level principles and best practice in relation to technology use for organisations that provide services to people with dementia.

Activities

Involving people with advanced dementia in meaningful activities can be extremely difficult as communication becomes increasingly problematic. Communication difficulties can often be at the root of difficult situations that might arise involving people with advanced dementia. These were historically and sometimes still are treated with medication, however, non-pharmacological interventions provide a wide range of approaches and potential benefits.²⁵ These approaches may be categorised in terms of their impact on the behaviour, emotion, stimulation or cognition of people with dementia.²⁵

Music therapy is one example of a non-pharmacological intervention, and it is reported to provide a means of relaxation and engagement for individuals with advanced dementia.²⁶ Music is also incorporated into the Namaste Care programme which also includes the use of therapeutic touch and life review in providing meaningful activities for people with advanced dementia.²⁷ An evaluation of the Namaste approach indicated a decrease in delirium indicators and agitation in people with advanced dementia.²⁸

Communication

As speech may not be available as a means of communication for people with advanced dementia, it becomes necessary to regard communication as something more than just talking. For example, in recent years several creative communicative approaches have been developed for working with people with advanced dementia and their impact evaluated.^{1,3,4,29} By and large, these interventions make use of the retained communication behaviours of people with advanced dementia (such as sounds, movements and eye gaze) to help caregivers to re-engage with these individuals on a non-verbal basis.^{1,3,4,29}

The work of Ellis & Astell (2011) is one example. They developed a technique called 'Adaptive Interaction' that facilitates meaningful interactions between people with advanced dementia and their caregivers. The approach is based on the caregiver using the same behaviours, movements and sounds that the person with dementia uses to form the basis of interactions. In this way the person with dementia guides the interaction. The use of this approach has shown increases in social interaction, laughter and touch by people with dementia and has indicated improved job satisfaction and attitude towards people with dementia in care staff.¹

Zoutewelle-Morris's 'Creative Interaction' approach also focuses on non-verbal communication by basing activities on hand movements and other gestures, holding physical objects and simply 'being there'.³ She suggests that the caregiver skills required for this type of interaction should be regarded as essentials rather than luxuries in dementia care.

John Killick and Kate Allan led the Good Sunshine Project, which addressed the improvement of communication for those with very advanced dementia and aimed to understand more about their experiences and needs.⁴ This project involved the caregiver tuning into the non-verbal communication of each individual and responding both creatively and sensitively.

The 'Talking Mats' resource allows people with dementia at all stages to express themselves without the need to use speech. The technique incorporates symbols and a simple scale with a presentation mat which allows users to organise their thoughts and express them in a visual format. The Talking Mats approach to communication has been used and assessed extensively and has been well received by caregivers and people with dementia alike.²⁹

Pain

Experiences of bodily pain in individuals with advanced dementia are very often missed and are therefore left untreated.^{30,31} Research in this area has revealed a number of gaps in the evidence to support the effectiveness of the treatment of pain in advanced dementia.³¹

However, recent research using an observational tool called PAINAD has shown that is sensitive tool for detecting pain in people with advanced dementia and can be used to assess pain management strategies. However, the results showed that quite often feelings of distress can be confused with the experience of pain.³⁰

The experience of people living with advanced dementia

It is extremely difficult to access the experiences and opinions of individuals with advanced dementia due to severe communication impairment. However, this does not mean that we cannot do so at all. Findings of a review on awareness in people with advanced dementia indicate that people with advanced dementia retain an awareness of perceptual and sensory information.³² As such, people with advanced dementia remain connected to the world when using speech is no longer possible. Therefore, we may be able to access the more visceral experiences of those we care for.^{33,34} This may be achieved by the use of life story work – this involves a biographical approach to the care of each individual with dementia. The life events of each person are recorded and evaluated and are integrated into their daily lives. When dementia is at an advanced stage, it may be necessary for caregivers to gather the information for life story work with the family of the individual with dementia. The main aim of life story work is to record past and present experiences of each individual with dementia and to improve their care by using that information in their current lives.³⁵

The experience of family carers

Studies that directly address the experiences of caregivers are relatively rare.³⁶ However, one such study reports on the experiences of six family carers' views on how advance care planning contributed to end of life care for people with advanced dementia in one care home.³⁷ The family caregivers of all six residents were asked to describe the experience and care in the last few days before their relative died. Themes included: the role of the

advance care plan; the place of death; the use of the end of life care pathway; and the relationship with care staff.³⁷

Quality of life

We might reasonably imagine that the quality of life we experience would be related to our level of cognitive function.^{38,39} In fact, this may not be the case as a recent study has revealed that individuals with advanced dementia can experience good quality of life if certain elements of their lives are addressed, for example engaging in meaningful activities related to their interests, social engagement, an environment that affords interaction with others and positive staff attitudes.⁶ This is related to the findings of another review on quality of life in people with advanced dementia in terms of its assertion that it is hope regarding what people with dementia can achieve that is the attitude most associated with their quality of life.³⁸

Conclusion

The complexity of the needs of individuals with advanced dementia is poorly understood^{8,36} and legal issues surrounding decision-making in this area are complex.^{8,12,13,14} Individuals with advanced dementia are likely to have other life-threatening illnesses^{5,8} which has a huge impact on the costs of caring for people with advanced dementia.^{15,16, 17,19} Caring for individuals with advanced dementia can be extremely challenging^{19,20} and more research is required in terms of identifying ways of helping professional and family caregivers to cope.^{40,41} This will involve directly accessing the experiences of carers and gaining knowledge from them.^{40,41} Communication becomes particularly difficult as speech may not be available as a means of communication for

people with advanced dementia. As such, it becomes necessary to regard communication as something more than just talking. Several new approaches are addressing non-verbal approaches to communication which may benefit both individuals with advanced dementia and their caregivers.^{1,3,4,29}

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