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Nursing Older People

Paper 1: Changing needs in advanced dementia

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Abstract:	This is the first in a series of five articles on the topic of older people living with advanced dementia. Here we explore the changes that might happen as dementia progresses to the advanced period from the perspective of the individual, their family and other carers. The person living with advanced dementia is likely to experience physical, cognitive and social changes that can be profound and debilitating. Health needs intensify as new and co-existing problems create increasing dependency on others in activities of life and living. These activities can include eating, drinking, mobilising and support with personal care. As a consequence the family carer may find their role has to develop and change to provide increasing support in response to these complex needs. These increasing needs can lead to moves to other settings, such as hospitals or care homes and careful and collaborative management of care is crucial to maintain the quality of life for the person and family carer.
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Paper 1: Changing needs in advanced dementia

Abstract

This is the first in a series of five articles on the topic of older people living with advanced dementia. Here we explore the changes that might happen as dementia progresses to the advanced period from the perspective of the individual, their family and other carers. The person living with advanced dementia is likely to experience physical, cognitive and social changes that can be profound and debilitating. Health needs intensify as new and co-existing problems create increasing dependency on others in activities of life and living. These activities can include eating, drinking, mobilising and support with personal care. As a consequence the family carer may find their role has to develop and change to provide increasing support in response to these complex needs. These increasing needs can lead to moves to other settings, such as hospitals or care homes and careful and collaborative management of care is crucial to maintain the quality of life for the person and family carer.

Changing needs in advanced dementia

The introductory paper for this series explores some of the profound changes that might occur and can impact on behaviour, emotions, senses, interaction and communication (Zeisal, 2010). Older people with advanced dementia may also experience age related changes together with new and longstanding health conditions (Livingston et al. 2017). This will increase with advancing age, research indicates approximately 20-25 per cent of people with advanced dementia are 80 years and older (Lucca et al. 2015). Conversely, the presence of dementia also increases the impact of age-related diseases and disabilities and risk of mortality (Snowden et al. 2017). The older person with dementia is more likely to be admitted to hospital and up to 25 per cent of hospital bed days are for people over 80 years old (HSJ/Serco, 2014).

Dementia is understood as a syndrome rather than a single illness and symptoms usually involve deterioration in memory, thinking and behaviour, leading to a reduced ability to perform activities of living (The World Health Organization, 2019). The most common conditions causing dementia are Alzheimer's disease (62 per cent), vascular dementia (17 per cent) and dementia with Lewy bodies (four per cent); it is possible to have more than one of these conditions at the same time and this is called mixed dementia (Prince et al. 2014). These different conditions can present in particular ways. For example, the person with Alzheimer's disease may show a slow and progressive decline in memory, language and visual spatial skills. In vascular dementia, progression is more erratic, with an irregular and sometimes stepwise pattern of progression. Early on in dementia with Lewy bodies, word-finding and visuospatial difficulties can occur, together with poor mobility and frequent falls

(Alzheimer's Research UK, 2018). Yet even within specific diseases, each person is an individual and will have a personal experience of their progress through dementia. Rahman et al. (2018) suggest that a more positive approach would focus on a person's strengths and remaining abilities.

Changing responses in advanced dementia

While maintaining a positive and enabling approach throughout the care experience, there are undoubtedly challenges for family carers and practitioners. Changes in brain function caused by the ageing process and advanced dementia can create a profound decline, evident in the person's reduced ability to independently perform activities of living. These include nutrition, hydration, elimination and sleep. Neurological changes in the brain can also create motor or movement problems for some people. Specific cognitive deficits can impact on activities of living, for example memory, understanding, planning and perception. Early in the condition this may include instrumental activities of living such as managing finances, cooking and taking medication correctly (Giebel et al. 2015a). Later the impact can extend to the most fundamental activities, such as washing and dressing, going to the toilet, eating, drinking and moving around. Attempts have been made to link these changes in functional ability to each different stage of dementia and provide guidance. This not only includes what may happen to the person but also how to make positive improvements in the way care needs can be addressed (Shankle et al. 2013).

The term advanced dementia infers that there are a series of stages in the condition, although criticised as being inconsistent with individualised or person-centred care (Small et al. 2007). Despite this, rating scales are available that indicate when the person might be progressing to advanced dementia. These include the Functional Assessment Staging Tool (Reisberg et al. 2006) and the Bedford Alzheimer Nursing Severity Scale (Volicer et al., 1994). However, staging tools are only an indicator of the progression of dementia and are influenced by the person's personality, life experience, intelligence and resilience. Such abilities and strengths are individual and it is vital to assess and plan care with the involvement of the person, supported by family carers and other caregivers. More recently a global and person-centred definition of advanced dementia has been developed that may begin further discussion. This collaborative process with family carers, health, social care and charitable groups has led to the McLeish report (Alzheimer Scotland, 2019) (see Figure one).

(Box one here)

While the consequence of brain changes described above have considerable cognitive and physical impact, emotions can play a positive role in the person's experience. The person with advanced dementia continues to experience a range of emotions, expressed in different ways as dementia progresses. With the reduction of verbal language, lack of stimulation and limited opportunities to express emotions, other people become pivotal in the communication process (Cohen-Mansfield et al. 2012). Learning how the person is experiencing and expressing emotions will enhance the experience of providing care. In a study of people living with 'severe' dementia, a varied expression of emotion was identified ranging from small facial changes to smiling and crying (Brown, 2016). These subtle nonverbal communications could be missed by staff in this study, yet family visitors were more aware, suggesting that sharing such recognition could enhance communication.

Guaita et al. (2009) demonstrated that a person with advanced dementia can experience and display emotion when responding to photographs of familiar staff members, especially where the images show positive emotions. A range of active responses were observed to human interaction, contact with pets and music in a study involving 193 residents with advanced dementia (Cohen-Mansfield et al. 2012). In our own pilot work exploring personalised sensory interventions within advanced dementia day care, we observed and shared with family members, 'in the moment' photography, that captured facial expressions conveying moments of happiness (Tolson et al. 2015).

A devastating aspect of advanced dementia is the changing ability to communicate using language, limiting the ability to express needs and desires. By communicating using the body and facial responses, the person with advanced dementia can speak without words. Brown (2016) using a case study approach, identified a range of facial expressions, action and gestures identified by family and staff as meaningful. When the people with severe dementia in this study smiled, looked at someone or moved away they were perceived by others to do this with intent and purpose. Kontos (2004) refers to this as 'embodiment' when people with dementia communicate without words in a meaningful way using the face and body.

Complex health needs in advanced dementia

Informed practitioners must be alert to other possible co existing physical and mental illnesses, as well as new and unexpected conditions (Subramaniam, 2019). There are a wide range of diseases and conditions that may co-exist in advanced dementia, included here are frailty, delirium and depression. Frailty, as it is not clearly identified as co-existing with advanced dementia; delirium, for the potential impact on the person if untreated and depression, because there is a lack of recognition and active management.

Frailty and dementia

The syndrome of frailty is both a cause and a consequence of progression of dementia. A recent study by Abreu et al. (2018) found that approximately 17 per cent of people with advanced dementia living in the community demonstrated severe frailty and high levels of dependency for functional activities. Frailty involves a loss of recovery and resilience as the body loses reserve, with between 25 and 50 per cent of people 85 years and older affected (Clegg et al. 2013). As the person who is frail normally fails to return to normal functioning after any acute illness, there is an increase in outcomes such as delirium, falls and deterioration in activities of living (Clegg et al. 2013). Indicators of frailty include weight and muscle loss, exhaustion and reduced speed of movement. These indicators are included in the Comprehensive Geriatric Assessment tool (CGA), which identifies medical conditions, mental health status and the person's social and living conditions (British Geriatrics Society, 2019). The person with advanced dementia and frailty will have complex health needs with multifaceted causes and a holistic assessment such as the CGA is crucial to good quality care outcomes.

Delirium and dementia

Living with advanced dementia increases the risk of delirium as changes in the brain lead to disturbance of the cholinergic neurotransmitter systems, reduced oxygen perfusion through the brain and disturbance of the sleep wake cycle (Kurrie et al. 2012). Other risk factors that increase in advanced dementia include infections, unrelieved pain, acute illness and the effects of some medication. If the person develops delirium this is likely to lead to increased mortality and morbidity, risk of falls and longer recovery time (Apold, 2018). Diagnosis of delirium in the presence of advanced dementia is critical and requires excellent assessment, observation skills and knowledge. Care interventions should include an emphasis on treatment of acute infection or pain, hydration, medication review, sleep hygiene and care at home with family where possible (Ford, 2016).

Depression and dementia

Depression is considered common throughout the course of dementia and challenging to recognise or assess yet has been linked to increasing functional and cognitive impairment (Kverno and Velez, 2018). A European study of 2,014 people with severe dementia living across eight countries found 30 per cent had depression, mainly associated with factors such as pain and distressed behaviour (Giebel et al., 2015b). Recognition and assessment of depression in advanced dementia is challenged by increasing difficulties with communication, so the person may not be able to express how they feel (Giebel et al. 2015b). This can be addressed by a review of the person's physical and

mental health history, collaboration with those who know the person well, such as family and caregivers and support from formal assessment tools. The usual assessment scales for depression require verbal skills and this limits their value for people with advanced dementia. The Cornell Scale for Depression in Dementia (CSDD) (Alexopoulos et al. 1988), does not require verbal responses and depends on information from family and caregivers. There is also a subscale for depression in the more extensive Neuropsychiatric Inventory, Nursing Home (NPI-NH) version using observational information (Cummings et al. 1997).

Medication as treatment of depression in dementia is controversial and a recent Cochrane review found inconclusive evidence of benefit from the use of antidepressants, with little effect on daily activity or cognition and adverse effects were common (Dudas et al. 2018).

Changing care needs

These changing needs are examined here and a later paper in this series will explore the support and nursing care required. These complex and changing health needs experienced by the person have consequences for fundamental care. Fundamental care has been a poorly developed concept and a recent Delphi study has produced a conceptual framework describing three elements, physical, psychosocial and relational (Feo et al. 2018). Physical aspects include nutrition, hydration, elimination, mobilising and sleeping framed within a psychosocial approach of enablement, dignity, respect and relationships that are compassionate and supportive. Richards et al. (2018) challenged the lack of evidence for practice and carried out a systematic review of fundamental care in nutrition, mobility, personal hygiene and elimination. This was found to be lacking in quantity and quality.

Weight loss occurs in most people with advanced dementia because of eating, chewing and swallowing difficulties and creates ethical concerns and emotional distress for family and caregivers. Some of the reasons for these problems are neuropathological and caused by loss of brain cells or mini strokes, impacting on the mechanics of eating and drinking. However, poor oral health, lack of appetite, difficulty recognising food or utensils and being unable to use cutlery or hold cups can all make this worse (Harwood, 2014). Swallowing difficulties may be an outcome of advancing dementia and can be aggravated when the person has acute health problems. The reduced ability to swallow safely can create serious risks such as aspiration, occurring in about 30 per cent of people with advanced dementia, leading to hospital admission and increased risk of death (Harwood, 2014).

Urinary and faecal incontinence can occur as dementia advances and verbal communication is lost. Constipation and faecal incontinence can be related to poor intake of food and fluids, lack of

mobility and adverse effects of some medications (Russell et al. 2017). A move to a different setting such as a hospital or care home, can create changes in routine, diet, medication and environment, increasing the likelihood of continence problems (Alzheimer Europe, 2014). Nonetheless, incontinence is not inevitable until the most advanced stages of the illness and can be the result of poor assessment and interventions.

As dementia increases in severity, the person can experience progressive motor problems, such as 'paratonic rigidity' (Reisberg et al. 2006). This results in the person being resistant to passive movement of the body initiated by others. This reaction is not in the person's control but can mimic a pulling away from the caregiver's actions. Increasing rigidity also reduces active movement and walking independently. At the severe stages of dementia early reflexes begin to emerge, including the grasp reflex. Here contact with another person or object can create a strong grip action. The person has no control over this response, but the caregiver can encourage this to release by gently stroking the back of the hand or arm (Kovach, 1997).

New onset seizure activity may occur in up to 23 per cent of people with dementia, mainly in advanced dementia (Asadollahi et al.2019). A loss of neurones, increase in amyloid proteins, blood vessel changes, electrolyte imbalance and loss of the inhibitory mechanisms within the brain, make seizures increasingly likely in some forms of dementia (Kurrie et al. 2012). Some seizure activity can be difficult to identify, as it can mimic transient ischaemic attacks (TIAS), syncope, delirium or frequent falls. Often it is more important to exclude other causes, such as brain tumours, head injury and adverse effects of medication, before beginning any form of treatment.

Sleep becomes more fragmented in older age and people living with dementia are more likely to experience sleep disturbance in the earlier rather than the advanced stages of the illness (Cipriani et al. 2015). The deterioration in the brain can include areas that control sleep such as the brain's biological clock and the suprachiasmatic nucleus which can disrupt sleep rhythms and patterns (Cipriani et al. 2015). Health related issues, such as pain, hunger, thirst, delirium, depression and adverse effects of some medications can make sleep restless and intermittent.

Changing needs of family carers.

UK and international healthcare policies promote services that enable the person to live in their own home (Scottish Government, 2013; Alzheimer's Disease International, 2016). This well-intentioned policy imperative however can be difficult to deliver in the absence of an effective care infrastructure to support and enable family caring; services can fall short of what is needed (Tolson et al. 2016). The financial costs associated with advanced dementia care (residential and non-

residential care) within Scotland has been estimated at £50.9M (Alzheimer Scotland, 2019). The actual monetary cost to the family varies and is influenced by local variations in the cost of care. In the UK, it is estimated that two thirds of the average annual cost for individuals of £32,250 is paid for by people living with dementia and their families (Alzheimer's Society, 2019). This is in sharp contrast to other conditions, such as heart disease and cancer, where the NHS provides care free at the point of use. Paying for care and worries about the financial cost of care to the individual and or family is one of the most frequent reasons for individuals calling the Dementia Telephone Helpline (Alzheimer Scotland, 2019). Yet the cost of care is not confined to monetary impacts, as caring has many other consequences.

As family carers occupy a central position in decision making about the person with advanced dementia it is important to pay attention to their support needs particularly during transitions in care (Schulmann et al. 2017). There are positives within caring relationships, for carers these include a sense of self-worth, improved confidence and a sense of pride in caring well for the person (Lloyd et al. 2016). However, other studies consistently report that carer's experience emotional overload, mental and physical disorders and loss of well-being (Dawood, 2016; Terum et al. 2017). Depression and other stress related mental health disorders are perceived to be a risk of sustained family caring (Sallim et al. 2015). There is compelling evidence to demonstrate that family carers often feel that they lack the knowledge and support required to sustain their caring roles (Hanson et al. 2016). In the absence of effective support family carers can lose their own social networks, withdraw from leisure pursuits and paid work. Access to information and training in caregiving for families is generally considered to be essential and particularly important within advanced dementia care (Alzheimer's Disease International, 2016). There is no doubt that caring for a relative living with advanced dementia is an emotive and exhausting time, particularly as they move closer to preparations for end of life care.

Recent case study research undertaken within seven European Countries which included 56 interviews, 23 with family members, revealed the positive impact of information that helped family members to feel included in care decisions and to anticipate changes ahead. Where services were fragmented, communication poor and families felt unable to influence care decisions the experience of care was described as substandard (Lillo-Crespo et al. 2018). Although family carers are central to decision making in advanced dementia, the wishes and preferences for end of life care of the individual are not necessarily known or aligned with the views of family members (Harrison-Denning et al. 2012). This creates questions and concerns about the capacity of the person with dementia to be involved in decisions and can fuel tensions between family members who may disagree.

Care transitions

It is acknowledged that it can be very hard for people with a diagnosis of dementia to imagine their future, including those that may be associated with transitions to different care settings and moving out of the family home. However, some transitions are unavoidable, and may be essential for the person's wellbeing and should be managed carefully. What is clear from the available evidence is that a person-family centred transitional model ideally includes timely (early) provision of information about choices and care goals based upon preferences, rather than a transition in response to a crisis (Hirschman and Hodgson 2018). An early transition point, often overlooked, could be pivotal if managed well; that is when standard day services can no longer meet the needs of an individual with advanced dementia. Such daily respite is thought to sustain family caring and be instrumental in delaying or preventing admission to long term care (Neville et al. 2015). Unfortunately, the intensity of care required by people with advanced dementia means that their care requirements are difficult to meet within standard day care services, giving rise to calls to develop 'enhanced stage-specific day care services' to maximise these benefits (Silverstein et al. 2010). One of the few examples of an advanced dementia day care service is reported by Tolson et al (2015) who positively evaluated a pilot service focussed on enhanced sensory care delivered in partnership with family carers.

Because people with advanced dementia have such complex health needs, these transitions include hospitals, which should be avoided where possible as these can be distressing and generally do not prolong life (Livingston et al. 2017). Unnecessary or unwelcome transition to hospital can contribute to further decline in the person's health and wellbeing (Sivananthan and McGrail, 2016). Despite this admission to hospital is increasing and can be harmful and costly (Sommerlad et al. 2019) and stays are likely to be longer with higher risk of mortality (Guijarro et al, 2010).

The move to a care home is a pivotal transition for the person and the family carer. Despite the realisation that this may be essential to the person's wellbeing, family carers are often unprepared, reporting feelings of guilt and self-doubt (Müller et al. 2017). In a recent review, Hirschman and Hodgson (2018) highlight that when transitions are unplanned, they are particularly stressful for the individual and family. They recommend development of a transitional continuum aligned with the progression of dementia. Müller et al. (2017) also call for more attention to interventions that support the person and family carer throughout this transition process. While there is a general acceptance that admission to some form of continuing care is what most families anticipate, there is a paucity of research related to advanced dementia care transitions.

Conclusion

Advanced dementia has a profound impact on the individual and their family and the associated care and nursing needs are complex. It follows that nurses who have advanced dementia care knowledge and skills can sensitively work with both the individual and their family in ways that will enable all to live the best life possible. This involves appreciation of how to work with the person's strengths, preserved functions, emotional connections and being responsive to nonverbal expressions of need.

Much can be done by nurses, family and carers, with the necessary knowledge, will and skills to support and intervene as early as needs are identified. Acute and chronic conditions must be identified, addressed and the fundamentals of care must be supported effectively. This positive and dynamic approach to care needs can improve the person's quality of life. Where care needs create transitions to other care settings, this should be anticipated, and advance planning developed. The increasing complexity of health needs and interventions create a situation where the person, their family and carers will benefit from the support from nurses who have developed specialised knowledge in the care of the person with advanced dementia.

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Box one

The Fair Dementia Care Commission Report (Alzheimer Scotland, 2019) defines advanced dementia as:

“Advanced dementia is associated with the later stages of illness when the complexity and severity of dementia-related changes in the brain lead to recognisable symptoms associated with dependency and an escalation of health care needs and risks. Addressing advanced dementia related health needs requires expert health care, nursing and palliative care assessments together with insights provided by family carers and others, particularly when the person has difficulty communicating their own needs and emotions. Advanced dementia involves living, sometimes for years, with advanced illness and the advanced dementia continuum includes the terminal stages of death and dying. The experience of advanced dementia is unique to the individual and dependent on the aetiology of the underlying illness, comorbidities and other factors relating to health, personality, biography and socio-economics.”(p13-14).

Response to Editor and reviewer chart

Comment	Responses
Reduce word count	Now below 5,000 without references
Reduce repetition in nutrition and hydration	I have linked this section on fundamental care with the papers that follow and have revised and reduced all of this section.
Reference check	References reviewed and checked Older references replaced
Spell check	Checked
Page 5 ?physical or clinical	Changed to physical
Page 9 Would benefit to discuss increased risks /mortality etc	Additional comments and references
Page 3 'severe' instead of advanced	Severe retained as this was the defined population in the study
Page 4 inserted daily to activities of living	Our standard in pre-registration programmes is activities of living but if the journal prefers daily activities it can be adjusted