

## **Multimorbidity and frailty in people with dementia**

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### **Key words**

Dementia

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## **Abstract**

Many people with dementia will have other complex health needs including comorbidity and frailty. Most models of care focus on single diseases and do not take into account the needs of those with comorbidities and dementia. Integration, continuity of care and personalization are all particularly important for this vulnerable group. It is also important to recognize potential barriers to access to care so that these can be properly addressed. This article is based on work being undertaken for the National Institute of Health Research HS&RD programme.

## **Introduction**

The population is ageing and so the proportion of people with both dementia and multimorbidity and/or frailty is increasing. Despite this, health care systems and research often treat dementia as an isolated condition with little understanding of how other complex health needs might impact on patient and carer experiences or service use and provision. For nurses, it is increasingly the case that the presence of dementia complicates how they provide care for other health needs. In this paper we consider current issues around providing health care for people with dementia and complex health needs including management and organisation of care, access to care, models of care, the role of the family carer and prevention. We draw on research we are currently undertaking as part of an NIHR funded study on improving healthcare for people with comorbidity and dementia (Bunn et al., 2012a).

### **Dementia, multimorbidity and frailty**

Dementia affects one in 20 people over the age of 65 and one in five over the age of 80 (ADI, 2010). Over 800,000 people in the United Kingdom have dementia (Luengo-Fernandez et al., 2010), the most common form being Alzheimer's disease (Alzheimer's, 2007). This number is forecasted to increase by 40% over the next 12 years (Alzheimer's Society, 2014). Although there are significant differences in the physical and cognitive effects of the different types of dementias all are progressive, involve increasing physical and mental deterioration, and lead to people living with dementia becoming increasingly dependent. The prevalence of dementia in patients over 65 in general hospitals is high and it is estimated that at any one time a quarter of acute hospital beds are occupied by people with dementia (Royal College of Psychiatrists, 2013).

Dementia is primarily a condition of old age and as such many people with dementia will have other problems associated with old age including long-term health conditions (Doraiswamy et al., 2002, Schubert et al., 2006). The existence of several long term conditions in one individual (multimorbidity) is common in people with dementia and on average, people with dementia have 4.6 chronic illnesses in addition to their dementia (Guthrie et al., 2012). Common health conditions in people with dementia include diabetes, vascular or heart disease, chronic obstructive pulmonary disease, musculoskeletal disorders

and chronic cardiac failure (Doraiswamy et al., 2002, Leon et al., 1998) and there is increasing evidence to support an association between Alzheimer's disease and cardiovascular risk factors such as hypertension and hypercholesterolaemia (Skoog, 2000). In addition, delirium, infections, falls, urinary and faecal incontinence, constipation and epilepsy occur more frequently in people with dementia (Doraiswamy et al., 2002, Heun et al., 2013).

Clinicians and researchers are becoming increasingly interested in the concept of frailty in older people as something discrete from old age. Frailty has been characterised as a cumulative decline in many physiological systems during a lifetime and in people aged over 85, a quarter to a half are estimated to be frail (Song et al., 2010). This age-related decline leaves older people vulnerable to minor stressor events or sudden changes to health status such as an infection, minor surgery or a new drug therapy and at increased risk of falls, disability, long-term care and death (Clegg et al., 2013). Definitions of comorbidity, multi morbidity and frailty can be seen in Box 1.

### **Management of care for people with dementia and multimorbidity or frailty**

Navigating health and social care systems may be particularly difficult for older people with complex health needs, including those with dementia, frailty and multimorbidity. Poor communication between different professionals, lack of dementia awareness in non-specialist settings and a lack of coordinated working between practitioners in different settings is a barrier to the delivery of good care for people with complex health needs (Bunn et al., 2014a). We know that vulnerable older people require integrated and personalised health and social care delivered by a multidisciplinary team including generalists and specialists (Banerjee, 2014), however, how that is negotiated for people with dementia is not always clear.

#### *Continuity*

Continuity and consistency of care is also important for this group. Continuity may be considered as the degree to which different health care events are experienced as coherent and connected and consistent with the patient's needs and preferences (Haggerty et al., 2003). Freeman and colleagues have identified three main aspects of continuity:

relationship continuity, management continuity and informational continuity (Freeman et al., 2007). Relationship continuity refers to the continuous therapeutic relationship with one or more health professionals over time and is known to be important to people with dementia and their family carers. Relationship continuity between nurses and care recipients is key in promoting the delivery of person centred care for people with dementia (Aasgaard et al., 2014, Bunn et al., 2014b).

Older people with complex health needs value respectful delivery of services from health care professionals who are familiar with their needs and can help them navigate multiple services (Goodman, 2011, Ellins et al., 2012). Management continuity refers to the processes involved in coordinating, integrating and personalizing care and informational continuity refers to record keeping, the transfer of information and the timely availability of information for people with dementia, their family carers and the health care professionals looking after them. The increasing complexity of care that is delivered by a variety of providers means that information continuity is vital to the effective coordination of care (Crooks and Agarwal, 2008).

### *Self-management*

The main approach to the management of long-term conditions revolves around self-management that focuses on the attitudes and self-efficacy of the patient. Although it is desirable to support self-care for as long as possible, capacity for self-management will diminish as the dementia progresses. As a person living with dementia becomes unable to manage their own condition it frequently falls to family members or health care professionals to take on these tasks. For example in people with diabetes having dementia impacts on their ability to understand their condition and undertake self-care tasks such as managing medication and monitoring blood sugar (Feil et al., 2011b, Sinclair et al., 2000).

Older people with diabetes and dementia are at greater risk of hypoglycaemia than older people without dementia. In interviews we recently conducted, family carers of people with dementia and diabetes reported a number of ways in which dementia impacted on blood sugar control, resulting in hypoglycaemia and in some instances hospitalization (Bunn et al., 2012a). This included family members with dementia forgetting they had already eaten and

eating twice, or forgetting to eat at all. They also reported instances where family members had forgotten to take medication or taken medication (including insulin) more than once. Recent guidelines recommend that for people with dementia and diabetes, medication or insulin may need to be kept in a locked box until it is needed and that medication regimens may need to be simplified (Hill et al., 2013). We also found that as the person with dementia becomes unable to manage their own medication they find the administration of injections by someone else, for example a district nurse, distressing and painful.

### **Access to care**

There is evidence to suggest that people with dementia do not have the same access to treatment and monitoring as those with similar health conditions but without dementia (Bunn et al., 2014a). For example, people with dementia are less likely to receive monitoring for diabetes or cardiovascular related problems and have reduced access to treatment such as intravenous thrombolysis for stroke, or surgery for cataracts (Bunn et al., 2014a). There may be a variety of factors that contribute to this finding. People with dementia may be less likely to attend regular appointments or to notice or report relevant symptoms and they may be more reliant on carers to manage and facilitate appointments (Keenan et al., 2014). It is also possible that clinicians may be more reluctant to investigate and treat patients with dementia either because of the difficulties involved in gaining meaningful consent or because treatments are considered inappropriate for older patients with dementia and multimorbidity.

People with dementia may not receive appropriate and timely care because dementia overshadows other conditions meaning that problems can be wrongly attributed to the dementia rather than to other physical causes. This may especially be the case if the person with dementia is experiencing the behavioural and psychological symptoms associated with dementia (Piette and Kerr, 2006). Conditions such as diabetes or visual impairment may not be recognized in people with dementia because their symptoms are misinterpreted. For example, people with dementia who develop diabetes may appear to have a worsening of their dementia because symptoms of diabetes such as confusion due to elevated blood glucose or incontinence, are wrongly attributed to dementia (Hill et al., 2013). Likewise problems such as falling or not recognizing objects may be seen as signs of dementia

meaning that health care professionals fail to investigate the possibility that it is the result of some form of visual impairment. This is a major issue as some interventions, for example cataract operations, have the potential to improve quality of life and physical functioning for someone with dementia.

## **Models of care for older people with dementia**

### *Single issue focus*

Most models of care are focused on single conditions and do not take into account the needs of those with multimorbidities. Combining treatment recommendations for patients with multimorbidity may be inappropriate as it can result in harmful or burdensome treatment regimens and inappropriate polypharmacy. This may be particularly difficult for people who have dementia or who are frail (Guthrie et al., 2012). Patients with long term conditions are frequently managed by specialist nurses working to protocols driven by national guidelines (Salisbury, 2012). Such guidelines are not generally written to take into consideration the needs of those with multimorbidity or who have dementia. Likewise guidance on dementia tends not to take into consideration the needs of those with specific health problems like diabetes or stroke (Bunn et al., 2014a).

A number of initiatives have been developed to improve the care of older people with dementia in acute hospitals, including liaison psychiatric services (Holmes et al., 2010) or specialist units that combine medical and mental health care for older people (Goldberg et al., 2013). As yet it is not clear if such units provide better care for people with dementia. A randomised controlled trial of a specialist medical and mental health unit for people with dementia found no impact on length of stay, readmissions or mortality but the intervention seemed to improve patient experiences and family carers were more satisfied (Goldberg et al., 2013). It is, however, not clear if such units are suitable for all people with dementia. For example, a person with dementia being admitted after a stroke may need to be in an acute stroke unit, or a person undergoing surgery for cataracts on an ophthalmology ward. It is clear therefore that there is a need for all hospital and community services to be more aware of the needs of people with dementia.

An example of integration and personalization of care for people with dementia is the Gnosall GP surgery services for older people with dementia in Staffordshire. This model involves screening, assessment, and pre and post diagnostic support provided by a multi-disciplinary team including GPs, practice nurses, old age Psychiatrists, and voluntary sector support workers. There is an emphasis on person-centred care which takes into consideration the social context of each individual. This model has been positively evaluated and for the practice population it was shown to reduce the length of stay in acute hospitals for over-75s (Clark et al., 2013).

### **Support for family carers of people with dementia who have complex health needs**

Around two thirds of people with dementia live in the community (National Audit, 2007) with about 70% receiving care from family members. Estimates of the current number of family/unpaid carers of people with dementia in the UK range from 476,000 to 670,000 (National Audit, 2007). As the population ages, and the number of people with dementia rises, there will be an accompanying increase in the number of family carers looking after people with dementia, many of whom have multiple health and social care needs (Wimo et al., 2010).

Carers often play a significant role in coordinating and managing their family members care and in facilitating informational continuity. Despite this there is evidence that they often receive inadequate support in planning their relatives' care, that their contribution to managing their relatives' care is not always recognised and they are often excluded from decision making (Feil et al., 2011a). Moreover support after a diagnosis of dementia is frequently considered inadequate by family carers (Bunn et al., 2012b). Nurses should be aware of the importance of relationship-centred care that acknowledges the role of dementia care triads comprising the person with dementia, their family carer and the health and social care professional (Adams and Gardiner, 2005).

A recent report from the Carers Trust and the RCN describes the 'Triangles of care' model for dementia (Hannan et al., 2013). This model focuses on carer inclusion and support. It was originally developed for mental health service users and has been adapted to meet the needs of carers of people with dementia in acute hospital. The concept of the triangle of care requires that nurses are willing to collaborate, and engage, with the person with

dementia and the family carer and involve carers in decision about care and treatment for their relatives. The six key standards of the triangle of care model can be seen in Box 2.

### **Staff training and education**

In 2009, the National Dementia Strategy was launched setting out the workforce requirements to attain an informed and effective workforce for people with dementia (Department of, 2009). This meant that all health and social care staff involved in the care of people who may have dementia should have the necessary skills to provide the best quality care in the roles and settings where they work (HEE). The Health Education England (HEE) mandate has set out a three tier programme for dementia training for the NHS. Tier one seeks to ensure that all staff will be dementia aware and be able, as part of their everyday work, to provide dementia sensitive care and know how and when to direct patients and carers to appropriate support. Tier two and tier three training aims to build on this to provide in depth training for those in regular contact with people with dementia and develop key staff as experts and leaders in dementia care respectively (Health Education England 2012, 2014). The HEE training mandate is an important initiative to raise awareness of the needs of people with dementia across the NHS. However, there is a need for more detailed, evidence informed, education and training programmes that consider how the presence of dementia affects the treatment and care of other conditions.

### **Prevention of dementia, frailty and long-term conditions**

There is a well-established link between some common lifestyle behaviours and physical and mental health, with evidence that behaviours such as smoking, drinking, lack of exercise and poor diet can increase the risk of dementia, disability and frailty. The National Institute for Health and care excellence is in the process of developing public health guidance on mid-life approaches to preventing dementia, disability and frailty in later life (NICE, 2014). This guidance puts the emphasis on reducing behaviours that increase the risk of dementia, disability and frailty and reducing the incidence of long-term conditions that can contribute to disability and frailty (such as cardiovascular disease, diabetes, chronic obstructive pulmonary disease). This includes health promotion activities aimed at reducing smoking and alcohol consumption, increasing physical activity and improving diet. A recent study found evidence of a reduction in the prevalence of dementia in the older population over

two decades. The authors suggest that this could partly be due to successful primary prevention of heart disease and improved prevention of vascular morbidity (Matthews et al., 2013).

## **Conclusions**

The prevalence of comorbid conditions, multimorbidity and frailty in people with dementia is high. At present access to services may be poorer for many people with dementia and care may often be fragmented. Important considerations for improving health care for people with dementia and complex health conditions include continuity, integration and personalisation. Better communication is needed between different health care professionals and different specialties. Family carers often play a significant role in coordinating and managing family members care and their role needs to be acknowledged and valued by staff. Recent initiatives by Health Education England mean that tier 1 training that aims to raise awareness, in terms of knowledge, skills and attitudes for all those working in health and care, will have been completed by 250,000 health and care staff by March 2015. This is part of a larger programme that will ensure that relevant dementia training and resources will be available to all staff by 2018. Dementia, frailty and multimorbidity are not only the concerns of those caring for older adults. Health promotion in mid-life is also key in reducing the prevalence and impact of later physical and mental disability.

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Box 1

**Comorbidity:** the presence of more than one distinct condition in one individual.

Definitions tend to assume that one condition is assuming a central place (Feinstein, 1970)

**Multimorbidity:** the co-occurrence of multiple chronic or acute diseases and medical conditions within one person. One condition is not necessarily more central than the other. Term captures multiple, potentially interacting, medical and psychiatric conditions (Boyd and Fortin, 2010)

**Frailty:** A combination of the natural ageing process and a variety of medical problems. It has been suggested that if someone has three or more of the five following factors they should be considered frail.

- Unintentional weight loss (10 pounds or more in a year)
- General feeling of exhaustion
- Weakness (as measured by grip strength)
- Slow walking speed
- Low levels of physical activity

Box 2: The six key standards of the 'Triangles of Care Model'

- 1) Carers and the essential role they play are identified at first contact or as soon as possible thereafter.
- 2) Staff are 'carer aware' and trained in carer engagement strategies.
- 3) Policy and practice protocols regarding confidentiality and sharing information, are in place.
- 4) Defined post(s) responsible for carers are in place.
- 5) A carer introduction to the service and staff is available, with a relevant range of information across the care pathway.
- 6) A range of carer support services is available.

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