Multimorbidity and frailty in people with dementia

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Abstract

Many people with dementia 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 personalisation are particularly important for this vulnerable group. It is also important to recognise potential barriers to accessing care so that these can be addressed. Issues around providing health care for people with dementia and complex health needs are considered in this article, including management and organisation of care, access to care, models of care, role of the family carer, and prevention of dementia, frailty and long-term conditions.

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THE POPULATION IS ageing and the proportion of people with dementia and multimorbidity and/or frailty is increasing. Despite this, healthcare systems and research often treat dementia as an isolated condition with little understanding of how other complex health needs might affect service use and provision, and the experience of the patient and carer. For nurses, the presence of dementia may complicate management of other health needs. This article identifies issues around providing health care for people with dementia and complex health needs, with particular reference to research being undertaken as part of a study funded by the National Institute for Health Research on improving health care 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 people over the age of 80 (Alzheimer's Disease International 2010). More than 800,000 people in the UK have dementia, and the most common type is Alzheimer's disease (Alzheimer's Society 2014). This number is estimated to increase to more than one million by 2025 (Alzheimer's Society 2014). Although there are significant differences in the physical and cognitive effects of the various types of dementia, all are progressive, involve increasing physical and mental deterioration, and result in increased dependence. The prevalence of dementia in patients over the age of 65 in general hospitals is high and it is estimated that one quarter of acute hospital beds are occupied by people with dementia at any one time (Royal College of Psychiatrists 2013).

Dementia is primarily a condition of old age, and is, therefore, commonly associated with several age-related problems, including long-term health conditions (Doraiswamy *et al* 2002, Schubert *et al* 2006). Multimorbidity – the presence of several long-term conditions – is common in people with dementia and, on average, these individuals have an additional 4.6 chronic illnesses (Guthrie *et al* 2012). These illnesses or conditions may include diabetes, vascular or heart

disease, chronic obstructive pulmonary disease, musculoskeletal disorders and chronic cardiac failure (Leon *et al* 1998, Doraiswamy *et al* 2002). There is increasing evidence to support an association between Alzheimer's disease and cardiovascular risk factors such as hypertension and hypercholesterolaemia (Skoog 2000). Also, 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 interested increasingly 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. Between one quarter and one half of individuals over the age of 85 are estimated to be frail (Song *et al* 2010). This age-related decline means that older people are vulnerable to minor stressor events or sudden changes to health status such as an infection, minor surgery or a new drug therapy. They are also at increased risk of falls, disability, long-term care and death (Clegg *et al* 2013). Definitions of comorbidity, multimorbidity and frailty are provided 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. Barriers to the delivery of good care for these individuals include: poor communication between professionals, lack of dementia awareness in non-specialist settings and lack of co-ordinated working between practitioners in different settings (Bunn *et al* 2014). 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 care is negotiated for people with dementia is not always clear.

Continuity

Continuity and consistency of care are important for people with dementia. Continuity may be considered as the degree to which different healthcare events are experienced as coherent and connected, and consistent with the patient's needs and preferences (Haggerty *et al* 2003). Freeman *et al* (2007) identified three main aspects of continuity: relationship, management and informational continuity. Relationship continuity refers to the continuous therapeutic relationship with one or more healthcare 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 essential in promoting the delivery of person-centred care for those with dementia (Aasgaard *et al* 2014, Bunn *et al* 2015). Older people with complex health needs value respectful delivery of services from healthcare 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 co-ordinating, integrating and personalising care. Informational continuity includes record-keeping, the transfer and availability of information for people with dementia, their family carers and the healthcare professionals looking after them. The increasing complexity of care delivered by a variety of providers means that information continuity is vital to the effective co-ordination of care (Crooks and Agarwal 2008).

Self-management

The main approach to the management of long-term conditions involves self-management, which 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 dementia progresses. As people with dementia become unable to manage their condition, it falls frequently to family members or healthcare professionals to take on daily tasks. For example, people with dementia and diabetes may have a reduced capacity to understand their condition and undertake self-care tasks such as managing medication and monitoring blood sugar levels (Sinclair *et al* 2000, Feil *et al* 2012). Therefore, older people with diabetes and dementia are at increased risk

BOX 1

Definitions

Comorbidity – the presence of more than one distinct condition in one individual. Definitions tend to consider that one condition assumes a central place (Feinstein 1970).

Multimorbidity – the co-occurrence of multiple chronic or acute diseases and medical conditions in one person. One condition is not necessarily more central than the other. The term encompasses 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 following factors they should be considered frail (Fried *et al* 2001):

- Unintentional weight loss – ten pounds or more in one year.
- General feeling of exhaustion.
- Weakness, as measured by grip strength.
- Slow walking speed.
- Low levels of physical activity.

of hypoglycaemia compared with older people without dementia.

In interviews conducted by the authors, family carers of people with dementia and diabetes reported several ways in which dementia had an effect on blood sugar level control, resulting in hypoglycaemia and in some instances hospitalisation (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. Guidelines recommend that for people with dementia and diabetes, medication or insulin may need to be kept in a locked box until required and medication regimens may need to be simplified (Hill *et al* 2013).

Access to care

There is evidence to suggest that people with dementia do not have equal access to treatment and monitoring as those with similar health conditions but without dementia (Bunn *et al* 2014). 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* 2014). A variety of factors may 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 rely on carers to manage appointments (Keenan *et al* 2014). In addition, clinicians may be more reluctant to investigate and treat these patients because of the difficulties involved in gaining consent or because treatments are considered inappropriate for older people with dementia and multimorbidity.

People with dementia may not receive appropriate and timely care because dementia may overshadow or mask other conditions, resulting in problems being attributed wrongly to dementia rather than to other physical causes. This may be the case particularly if the person with dementia is experiencing associated behavioural and psychological symptoms (Piette and Kerr 2006). Conditions, such as diabetes or visual impairment, may not be recognised in these individuals because their symptoms may be 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 as a result of elevated blood glucose or incontinence, are incorrectly attributed to dementia (Hill *et al* 2013). Similarly, problems, such as falling or not recognising objects, may be seen as signs of dementia meaning that healthcare professionals fail to investigate the possibility that it is the result of some form of visual impairment. This is a major issue since some interventions, for example, cataract surgery, have the potential to improve quality of life and physical functioning for people 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 since 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 managed frequently by specialist nurses working to protocols directed by national guidelines (Salisbury 2012). These guidelines are generally not written to take into consideration the needs of those with multimorbidity or dementia. Guidance on dementia does not tend to take into account the needs of those with specific health problems such as diabetes or stroke (Bunn *et al* 2014).

Several initiatives to improve the care of older people with dementia in acute hospitals have been developed, including liaison psychiatric services (Holmes *et al* 2010) and specialist units combining 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 effect on length of stay, readmissions or mortality, however the intervention seemed to improve patient experiences and family carers were more satisfied with care (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 may need to be on an ophthalmology ward. It is evident, therefore, that there is a need for all hospital and community services to be more aware of the needs of those with dementia.

An example of integration and personalisation 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 multidisciplinary team, including GPs, practice nurses, old age psychiatrists and voluntary sector support workers. There is an emphasis on person-centred care that takes into consideration the social context of each person. This model has been evaluated positively, and for the practice population it was shown to reduce the length of stay in acute hospitals for people over the age of 75 (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 and approximately 70% of those with the condition receive care from family members. Estimates of the number of family or unpaid carers of people with dementia in the UK range from 476,000 to 670,000 (National Audit Office 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 will have multiple health and social care needs (Wimo *et al* 2010).

Carers often have a significant role in co-ordinating and managing their family member's care and in facilitating informational continuity. Despite this, there is evidence that carers often receive inadequate support in planning their family member's care; their contribution is not always recognised and they are often excluded from decision making (Feil *et al* 2011). Frequently, support after a diagnosis of dementia is 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 report from the Carers Trust and the Royal College of Nursing describes the Triangle of Care model for dementia (Hannan *et al* 2013). This model focuses on carer inclusion and support. It was developed originally for mental health service users and has been adapted to meet the needs of carers of people with dementia in acute hospitals. The Triangle of Care model requires that nurses are willing to collaborate, and engage with the person with dementia and the family carer, and involve carers in decisions about care and treatment for their relatives. The six standards of the Triangle of Care model are provided in Box 2 (Hannan *et al* 2013).

Staff training and education

In 2009, the National Dementia Strategy set out the requirements to attain an informed and effective workforce for people with dementia (Department of Health 2009). This was to ensure that all health and social care staff involved in the care of these individuals should have the skills to provide the best quality care in the roles in which, and settings where they work. The Health Education England (HEE) (2015) mandate has set out a three-tier programme for dementia training for the NHS. Tier 1 seeks to ensure that all staff are dementia aware and are 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. By March 2015, 250,000 health and care staff will have completed tier 1 training. Tiers 2 and 3 aim to provide in-depth training for those in regular contact with people who have dementia and develop staff as experts and leaders in dementia care (HEE 2015). This 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 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 (2014) is in the process of developing public health guidance on approaches in midlife to prevent dementia, disability and frailty in later life. 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,

BOX 2

The six standards of the Triangle of Care model

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

(Hannan *et al* 2013)

diabetes and 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 a result of successful primary prevention of heart disease and improved prevention of vascular morbidity (Matthews *et al* 2013).

Conclusion

The prevalence of comorbid conditions, multimorbidity and frailty in people with dementia is high. At present, access to healthcare 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 required between healthcare professionals in different specialties. Family carers often have a significant role in co-ordinating and managing the care of their family members and their role needs to be acknowledged and valued by staff. Dementia, frailty and multimorbidity are not only the concerns of those caring for older adults; health promotion in midlife is essential in reducing the prevalence and effect of physical and mental disability in later life **NS**

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