

Management of long-term conditions and dementia: The role of the Admiral Nurse

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More people are living longer in old age (World Health Organization [WHO], 2012). The numbers of those reaching the oldest ages are increasing the fastest: in 2008 there were 1.3 million people in the UK aged 85 and over, with this expected to increase to 1.8 million by 2018 and to 3.3 million by 2033 (Office for National Statistics, 2013). As life expectancy increases so people often develop a range of conditions and disabilities in the years before death (Froggatt et al, 2006). These changes to the age structure of the population influence both the prevalence and incidence of age-related conditions such as dementia (Stephan and Brayne, 2008).

Dementia and multimorbidity

Dementia is described as 'a syndrome which may be caused by a number of illnesses in which there is a progressive decline in multiple areas of function, including decline in memory, reasoning, communication skills and the ability to carry out daily activities' (Department of Health [DH], 2009). Alzheimer's disease is the most common type of dementia, affecting approximately two thirds of people with a diagnosis (Alzheimer's Research UK, 2016). Dementia is largely a disease of old age so many will also have other multimorbidity; such as, other long-term conditions, illnesses or disabilities. Multimorbidity is where two or more medical conditions or disease processes that are additional to an initial diagnosis co-exist and where one is not necessarily more central than the others (Boyd and Fortin, 2010). Multimorbidity represents the most common 'disease pattern' found among the elderly and is characterised by complex interactions of co-existing diseases where a medical approach focused on a single disease does not suffice. People with dementia show high levels of multimorbidity (Cigolle et al, 2007), including conditions that are long-term in nature such as cardiovascular disease and diabetes, and also risks associated with those conditions, for example musculoskeletal disorders such as fractures (Sampson and Harrison Denning, 2013).

Dementia and long-term conditions

A long-term condition (LTC) is defined as a condition that cannot, at present, be cured but is controlled by medication and/or other treatment or therapies (DH, 2012). The Scottish Government (2015) go further to define LTCs as health conditions that last a year or longer, impact on a person's life, and may require ongoing care and support. The number of people with one long-term condition is projected to be relatively stable over the next ten years, however, those with multiple LTCs is set to rise from 1.9 million in 2008 to 2.9 million in 2018 (DH, 2012). There are currently only four recommended pharmaceutical treatments

ABSTRACT

As life expectancy increases so people often develop a range of conditions and disabilities in the years before death. Multimorbidity represents the most common 'disease pattern' found among the elderly and is characterised by complex interactions of co-existing diseases where a medical approach focused on a single disease does not suffice. People with dementia who also have other comorbidities do not always have their comorbid conditions managed as those without dementia which often lead to a high number of hospital admissions with longer lengths of stay and greater treatment costs. This case study presents the case management approach taken by Admiral Nursing in managing the complexities where there is comorbidity of a long-term condition and a diagnosis of dementia. By empowering the person and their carer with information and choices and through good case management and communication, people can be supported to live well and avoid inappropriate hospital admissions.

KEY WORDS

♦ dementia ♦ Crohn's disease ♦ admiral nurse
♦ case study ♦ long-term conditions

for Alzheimer's disease, (National Institute for Health and Care Excellence [NICE], 2016) these medications cannot cure the disease but temporarily alleviate symptoms or slow down the progression of the disease (Alzheimer's Research UK, 2015). Whilst these medications are not indicated for all types of dementia it could be argued that dementia therefore meets the definition of being an LTC. Not surprisingly, people with LTCs and frail older people (including those with dementia) are the greatest users of health and social care (Kulmala et al, 2014). Frailty and dementia are multifactorial in origin and share some common aetiological pathways (Sampson and Harrison Denning, 2013). This rising demand on health and social care services has been of increasing concern and priority for policy development.

The NHS five year forward view (NHS, 2014) highlighted that long-term conditions take 70% of the health care budget and chronic care models have moved to focusing on more proactive, integrated services supporting better informed and empowered patients (Wagner, 2008; DH, 2005). Dementia is estimated to cost the UK economy £26 billion a year with diagnosis and NHS treatment costs alone attributed to around £4.3 billion (Alzheimer's Society, 2009).

People with multiple morbidities and LTCs are at risk of experiencing poor coordination of care and treatments that were primarily designed to address single conditions (House of Commons Health Committee, 2014). Lazaroff et al (2013) found that 95% of people with dementia receiving Medicare™ benefits in the USA had at least one other co-existing chronic medical condition, whilst a study in the UK found that, on average, people with dementia had 4.6 chronic illnesses in addition to their dementia (Guthrie et al, 2012). Hill (2002) suggests that people living with dementia and comorbidities do not always have their conditions managed as well as people without the dementia leading to longer hospital admissions, and greater treatment costs. Scruton and Urzi Brancati (2016) add that the progression of dementia in people with another comorbid illness appears more advanced by 1–2 years compared to a person without dementia. This may result in not only poorer quality of life for the person but also increasing associated health care costs.

This paper uses a case study approach to discuss the benefits of coordinated case management by an Admiral Nurse (see Box 1) in supporting better outcomes for a person with dementia with a comorbid LTC and their family carers.

Case study Section 1

(Names are anonymised to protect confidentiality in accordance with The Code (NMC, 2015))

Mrs S is a 79 year old lady who lives alone. She has one daughter, Lucy, who visits daily and is committed to ensuring her Mum has the best care possible. Lucy was referred to the Admiral Nurse service by her GP as she had many questions and uncertainties about her mother's dementia and any future decisions that might be necessary. Mrs S is also supported by a local care agency who visits four times a day to provide support with personal care and to ensure she receives adequate nutrition. Mrs S was diagnosed with

Box 1. Admiral Nursing approach (Rahman & Harrison Denning, 2016)

- ♦ Focus on the needs of the whole family affected by dementia, including psychological support to help the person with dementia and family carers to understand and deal with their thoughts, feelings and behavior, and to adapt to the changing situation. Caregiving involves a change in ongoing patterns of exchange between the caregiver and care recipient. Both the caregiver and recipient have to adjust to the transformation of their relationship into a caregiving relationship; this includes a change in the balance of roles, as the caregiver takes more responsibility for the welfare of the recipient. Admiral Nurses can offer expert input here.
- ♦ Use a range of specialist interventions that help people live well with the condition and develop skills to improve communication and maintain relationships. The current government-led dementia strategy emphasises early diagnosis, early interventions and support, inter-sectorial support and integrated working and support for carers.
- ♦ Work with families is an invaluable source of contact and support at particular points of difficulty in the dementia journey, including diagnosis, when the condition progresses, or when tough decisions need to be made, such as moving a family member into residential care. Anticipated problems are misdiagnosis, delayed diagnosis, and lack of information and services for people with dementia and their families, which gives rise to the risk for inappropriate management, crises, poor psychological adjustment to the diagnosis, reduced coping capacity and ability to forward plan.
- ♦ Help families cope with feelings of loss and bereavement as the condition progresses. There is an acknowledgement that family care does not end once "hands-on" caregiving ceases. Dementia guidelines support the principle that family carers should be supported during the illness of dementia and into bereavement. For family carers, the more social support that is received during the years of caregiving, the easier it is to adjust and adapt post bereavement.
- ♦ Provide advice on referrals to other appropriate services and liaise with other health professionals on behalf of the family. Such knowledge may help them provide general information, as opposed to just that which is medical (such as further diagnosis and management of medical problems). For example, a nursing specialist could potentially make timely referrals, if needed, to sources of specialist legal advice and use current legislation to reduce disputes.

Alzheimer's disease two years ago although it is likely that her difficulties predated the diagnosis for some time and is now in the moderate to advanced stages of dementia. Due to the disease process she has marked expressive dysphasia which manifests itself in a difficulty in making meaningful sentences, which has resulted in her using only 'yes' or 'no' responses. It is not always clear whether she comprehends what is being said to her making decision making especially difficult. Mrs S was also diagnosed with Crohn's disease (see box 2) in 2015 following a number of admissions over several months to the local acute hospital with abdominal pain, diarrhea, increased confusion, and dehydration. Initially, she was treated symptomatically and discharged, however, due to the repeated admissions she had further exploratory investigations leading to the diagnosis of Crohn's disease.

It would seem unusual for someone to be diagnosed with Crohn's disease at the age of 77, as with Mrs S, however,

evidence suggests that in people where there is already a diagnosis of dementia comorbid conditions are often not identified until their signs and symptoms become severe (Sampson et al. 2009). There may be many reasons for this including the ability of the person with dementia to articulate their symptoms or how they are feeling; as we know, Mrs S had an expressive aphasia, which resulted in marked communication difficulties. However, this may often be seen where there is a diagnosis of dementia. Other comorbid illnesses may be missed due to the overshadowing of the diagnosis of dementia where others may attribute their behaviours and signs to the dementia rather than an underlying physical pathology (Kostopoulou et al, 2008).

Much of the research on dementia and other comorbid illnesses tends to focus on diabetes and hypertension (Scrutton and Urzi Brancati, 2016) but these diseases are often associated with the causal factors of dementia rather than being unrelated but additional comorbid illnesses. A search revealed little or no research that specifically considered issues of the comorbidity of dementia and Crohn's disease.

People living with dementia are less likely to have good management of their LTC, as we have discussed, whilst the principle of chronic care models is to promote better informed and empowered patients in managing their own LTCs (Wagner, 2008) may defy equitable application in dementia.

Case study Section 2

Because of her expressive dysphasia, Mrs S was not always able to reliably communicate how she was feeling and whether she had pain. Subsequently, Lucy and her GP found it difficult to recognise when Mrs S was becoming unwell. Over the last two years this has led to numerous admissions to the local acute hospital as a result of a flare-up with her Crohn's disease. Often the first reliable indicator of a relapse in her Crohn's disease has been a blood test showing increased inflammatory markers, by which time Mrs S was particularly dehydrated and unwell and was admitted to hospital.

People with dementia often do not have a good experience in hospital. Their stay is often longer and outcomes are poorer than those without the condition (Sampson et al, 2009). Over a third of people dementia who are admitted to hospital are discharged to a care home and the longer their length of stay, the worse the effect on the symptoms of dementia and physical health (Alzheimer's Society, 2009). Anecdotally, this was supported by Lucy's description of the decline in Mrs S's mental health and level of frailty following each admission. Health professionals suggested Mrs S should move into residential care. Based on her knowledge of her mother wishes, Lucy believed that she would want to remain at home as long as possible and currently felt that her needs were being met at home with her care package and through her support; it just seemed difficult to manage her Crohn's disease in light of her co-existing diagnosis of dementia.

Box 2. Definition of Crohn's disease (www.CrohnsandColitis.org.uk)

- ♦ Crohn's disease is a condition that causes inflammation of the digestive system or gut. It can affect any part of the gut, though the most common area affected is the end of the ileum (the last part of the small intestine), or the colon. The areas of inflammation are often patchy with normal gut in between. Such a patch of inflammation can vary in its length, from only a few centimeters or to quite an extended portion. As well as affecting the lining of the bowel, Crohn's disease may also affect deeper layers of the bowel wall. Crohn's is considered a long-term condition although there may be periods of good health (remission), as well as times when symptoms are more active known as relapses or flare-ups. Symptoms can vary from person-to-person but may include mouth ulcers, abdominal pain, poor appetite, diarrhoea and fatigue.

Case study Section 3

When I first met Mrs S and Lucy I undertook a comprehensive assessment using the Admiral Nurse Assessment Framework (Harrison Denning, 2010). The framework covers 18 domains including physical and mental health of the person with dementia as well as exploring the needs, plans and life balance for the family carer. During the assessment it became apparent that Mrs S appeared to be living well with her dementia, however, Lucy's main concern was the management of her mother's Crohn's disease comorbid with her dementia. Mrs S had recently received a diagnosis of dementia following assessment at her local memory assessment clinic but had had no ongoing follow up; the expectation was that they would become re involved if there were significant changes in the presentation of her dementia. Lucy worried her mother did not always receive the same considerations for the treatment and management of her Crohn's disease because of the addition of her dementia. Despite having both dementia and Crohn's disease, Mrs S had little monitoring of either disease with responses of services appearing to be a crisis reaction rather than preventative which were likely to result in a hospital admission. Although the GP was supportive, home visits were always as a result of Lucy raising concerns about a change in her mother's condition.

People with dementia are less likely to receive the same help and coordination to manage and treat their comorbidities and LTCs than people without dementia. There are challenges in managing multiple comorbidities and LTCs in dementia, for example, they are less likely to receive annual monitoring of their LTC (Scrutton and Urzi Brancati, 2016) or receive effective pain relief (Harrison Denning, 2016). Effective support in the management of a LTC for a person with dementia is often more aligned to supporting and empowering family carers.

Case study Section 4

Following assessment, the first negotiated plan was to try and avoid further hospital admissions by supporting Lucy

to understand her mother's Crohn's disease and the early indicators of relapse. I always included Mrs S in the discussions around this as although she has advanced dementia with limited verbal communication; I felt it important that she had the opportunity to be involved in decision-making where possible. Whilst Lucy clearly had her mother's best interests at the forefront of decisions, failure to include Mrs S would have excluded her 'voice'. This decision was validated when Mrs S became very agitated when Lucy and I were talking about where Mrs S's needs would be best met. Despite her difficulties in communicating Mrs S was able to make it very clear that she wanted to remain at home as long as possible; through the use of closed questions and checking Mrs S was able to understand and contribute to the choices she was being offered.

I provided information about the recognised signs and symptoms of Crohn's disease and how these might manifest themselves in a person with dementia. This prompted Lucy to ask questions about the disease processes and likely prognosis. This highlighted Lucy's limited understanding of Crohn's disease and that she had not asked the consultant about available treatment options. We talked through how Lucy might be able to address this and who the best person to talk to might be. At the hospital out-patient appointment for Mrs S's Crohn's disease, Lucy felt confident enough to ask about treatment options, explaining that she felt that her mother's treatment was more reactive rather than preventative, which always seemed to result in an admission to hospital. Medication options were considered and as a result, Mrs S was commenced on an Adalimumab (Humira) subcutaneous injection. The Crohn's disease specialist nurses visited Mrs S at home to give the first injection and then taught Lucy to administer the injection every 2 weeks. This resulted in Lucy feeling more in control of the situation and her mother appeared to understand and consented to the treatment.

The next step was to support Mrs S and Lucy to better recognise when there was a potential relapse in the Crohn's disease. Mrs S was unable to express how she felt prior to a flare up but Lucy and the regular carers felt the first sign was a poor appetite and Mrs S was more likely to refuse foods she normally liked. Both poor appetite and potential dehydration are recognised symptoms of Crohn's disease (see *Box 1*). Lucy now recognised several of these symptoms occurring in her mother prior to a full relapse, especially poor dietary intake and general tiredness as well as eye inflammation. The carers were asked to detail Mrs S's diet and fluid intake on a daily basis and communicate this with Lucy. Mrs S was also weighed by Lucy on a weekly basis. This enabled all parties to be much more vigilant to any subtle changes in appetite in order to identify an early flare up with her Crohn's disease and importantly reduced Mrs S's risk of admission into acute care by responding to early signs of relapse.

Abdominal cramps are a common symptom in Crohn's disease; however, it may be difficult to detect pain in a person with dementia. Mrs S had a marked expressive dysphasia so may not have always reliably been able to express her pain or the site of any pain. The difficulty of recognising pain in

people with dementia is well documented. Pain is common in people with advanced dementia but is often under-diagnosed and under-treated (Scherder et al, 2009). Morrison and Sui (2000) found that among people with a fractured neck of femur, those with a cognitive impairment were given one third of the amount of analgesic compared to people without impairment however there is no consistent evidence to suggest that people with dementia experience pain any less than people living without the disease. The difficulty appears to be both the way in which the person expresses their pain and the way that staff or carers interpret pain signals (Harrison Denning, 2016). There are a number of tools to enable care staff to more accurately assess pain in dementia.

Case study

Section 5

Previously Mrs S's pain had been poorly recognised and assessed so I discussed the use of observational pain scales with Lucy and the carers to help them to better identify when Mrs S may be in pain, as well as providing the scored evidence for other healthcare professionals. I introduced Lucy to the Abbey pain scale (Abbey et al, 2004), a tool designed to assist in the assessment of pain in people who cannot clearly communicate their needs. Whilst there are nearly 30 observational pain assessment tools available, I chose this one as is commonly used in dementia and relatively easy to administer (Chow et al, 2016). It provided Lucy and the regular carers with a framework to assess when Mrs S might be experiencing pain in order to facilitate a review of her analgesia and also to pick up early on signs of relapse. Observational pain assessment scales can be very useful when a person does not have the ability to communicate their needs in the usual way.

On one occasion during a hospital admission, Mrs S was asked if she wanted to receive additional treatment for her Crohn's disease to which she replied 'no'. When Lucy arrived visited she was informed her mother had 'refused treatment'. When Lucy took time to explain to her mother the reasons why she had been prescribed the medication, the benefits and risks, Mrs S indicated she would consent. Despite her expressive dysphasia staff often assumed that she had capacity to make particular decisions without fully completing a Mental Capacity Assessment. The Mental Capacity Act 2005 aims to support people to make decisions for themselves whenever possible, and to protect those who lack capacity by providing a flexible framework that places them at the centre of the decision-making process (Social Care Institute for Excellence, 2009). I discussed with Lucy and Mrs S how this situation could be avoided in the future. Unfortunately, Mrs S had not previously completed and registered a Lasting Power of Attorney (LPA), which meant that, where her views were unable to be elicited, any decision must be made in her best interests. In this case the person who has to make the decision is known as the 'decision-maker' and normally will be the carer responsible for the day-to-day care, or a professional such as a doctor, nurse or social worker where decisions about treatment, care arrangements or accommodation need to be made. As Mrs S did not have an LPA I

supported Lucy to understand her role in decision making on her mother's behalf and the process for documenting best interest discussions and decisions.

Research into the experience of people with dementia who are admitted to acute hospitals has identified that the information trail is not always clear and there is evidence that communication between hospital and the community is poor (Care Quality Commission, 2014). This is in direct contrast to recommendations within chronic care models that communication between health professionals should be clear and joined up (Scruton and Urzi Brancati, 2016). There is much that can be done to ensure that vital, personal information is to hand should an urgent admission to acute care be required. In order to address this I supported Mrs S and her daughter to complete a 'This is me'¹ document. This type of form that contains personal information or elements of a person's life story is invaluable in ensuring that key information, including diagnosis, medical history, personal history, likes and dislikes are documented to inform the care and interventions given to the person with dementia in an unfamiliar setting (Thompson, 2010). Completion of the form should ensure that staff are fully aware of Mrs S's needs in order to make any future admission less distressing.

Conclusions

Due to the increasing numbers of people living with LTCs there is a growing need to identify more innovative and effective ways of managing complex care needs. There are numerous theoretical frameworks of care delivery, including Wagner's chronic care model (1998) and the Innovative Care for Chronic care model (WHO 2002). Translating the frameworks into service delivery models has led to the development of The Kaiser Performance Triangle, the NHS and social care long-term conditions model (Randell and Ford, 2011) and, more recently, the House of Care (Coulter et al, 2013). Common elements within the models include the principles that care should be proactive, holistic, preventive and patient-centered; that is the patient needs to be at the centre of their care and an active partner rather than a medically led approach and that all health, social care and voluntary services need to work collaboratively together. At the centre of the House

of Care is personalised care planning involving collaboration between the person and professionals to support and develop the confidence and competence needed for effective self-management. The Admiral Nurse Case management approach works actively to support the whole family affected by dementia, so where a patient self-management approach may not be possible as the dementia progresses, then empowerment of family carers is essential.

As an Admiral Nurse I supported and empowered Mrs S and Lucy to better manage the Crohn's disease in the context of dementia with the result of preventing further inappropriate acute admissions by improving the daughter's knowledge and understanding of the Crohn's disease process and in observing for relapse indicators. We negotiated a care plan which included a crisis plan for when changes were identified. Although Mrs S was unable to reliably express

KEY POINTS

- ♦ People living with dementia often have high levels of comorbidity including conditions that are long-term in nature.
- ♦ The effect of the diagnostic overshadowing of dementia can lead to poor management of their comorbid illnesses due to behaviours and signs being attributed to the dementia rather than the underlying physical pathology.
- ♦ People living with dementia are less likely to receive support to manage and treat their comorbidities and long-term conditions.
- ♦ Clinicians should consider the person in the same way as any individual living with multiple comorbidities and not in the context of their dementia, thus maintaining their personhood and dignity.
- ♦ Families can be empowered to act as advocates for the person living with dementia in order to receive appropriate treatments and support the 'self' management of long-term conditions.

how she was feeling, which may have been a factor in previous poor management, I always included her in discussions around her care. Lucy was proactive and engaged from the beginning which enabled a good relationship with me and a positive advocate for her mother. In the 6 months prior to the involvement of the Admiral Nurse Mrs S had had four acute hospital admissions; no further hospital admissions have been required in the 7 months of receiving Admiral Nurse case management.

Admiral Nurses, because of their case management role, are proactive in the coordination and communication with other professionals involved (for example, GP, Crohn's disease nurses, dietician), this was done on an individual basis rather than through a multidisciplinary meeting, which, on reflection may have been a more time effective way to draw all disciplines together.

This case study has demonstrated the complexity of how an Admiral Nurse supports the management of comorbid LTCs, particularly where there is also a diagnosis of dementia. By empowering the person and their carer with information and choices and through good case management and communication, people can be supported to live well with their LTCs.

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CPD REFLECTIVE QUESTIONS





- ♦ Consider your area of work. What other long-term conditions do you see in people living with dementia and how do they impact on them?
- ♦ As a clinician, how do you ensure that people living with dementia have the same opportunities for the management of their comorbidities?
- ♦ Consider the barriers and challenges for family carers in supporting the person with dementia in the management of a long-term condition.
- ♦ What might you do to ensure the person with dementia's views and wishes are acknowledged when planning care and treatment?
- ♦ What changes could you make in your own practice as a result of this case study?

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