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Specialist clinical nurses have proved successful at improving cancer care. Could similar specialists improve the care pathway for people with dementia and their carers?

The need for specialist nurses in dementia care

In this article...

- The success of nurse specialists in other specialties
- How dementia nurse specialists could improve dementia care
- Why effective dementia care is increasingly important

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Abstract Rahman S, Harrison Dening K (2016) The need for specialist nurses in dementia care. *Nursing Times;* 112: 16, 14-17. Dementia awareness is on the increase but, in many cases, tangible improvements in care are yet to be seen. As specialist nurse roles have improved patient care and outcomes in other specialties – most notably cancer care – this article looks at their impact and asks whether there is a need for such roles in dementia care, to what extent patient and carer experiences might be improved, and how health and social care might come together with policy makers and third-sector organisations to secure positive change.

Discussions around dementia care have been full of battle-weary analogies for too long, but the war against lack of awareness of it will, at some stage, officially end with the successful recruitment of an arbitrary number of "Dementia Friends". Even with that magic number, however, there is no guarantee the fight against stigma, prejudice and discrimination will have been won.

The discussion about how we care for people with dementia desperately needs to move on; policy is stuck in a gear that contradicts the overwhelming clinical evidence in nursing both in the UK and around the world. It is a consistent finding now that people with dementia and their family and friends struggle to preserve a "pre-dementia self" while, at the same time, accommodating their diagnosis and assimilating the disease into a new identity (Bunn et al, 2012). While other approaches might happily co-exist, there is now an urgent need for trained specialist staff to work alongside people with dementia and their families.

The value of nurse specialists

It was not uncommon in 2014 for the prime minister, in Prime Minister's Questions, to proclaim the benefit of clinical nurse specialists in cancer. Service provision for cancer is now in a totally different place to that for dementia, with far more generous funding for specialist cancer nurses and explicit mention of them in national strategy and policy.

The first only English dementia strategy covered 2009-14 (Department of Health, 2009) and has been followed by an implementation plan (DH, 2016) in which CNSs are barely mentioned. This omission is wholly inconsistent with current best clinical practice. Over the last several years, even those in the cancer field report that growth in demand for cancer services has not been met by an associated adequate growth in capacity. There are significant workforce deficits, particularly in

Talking points

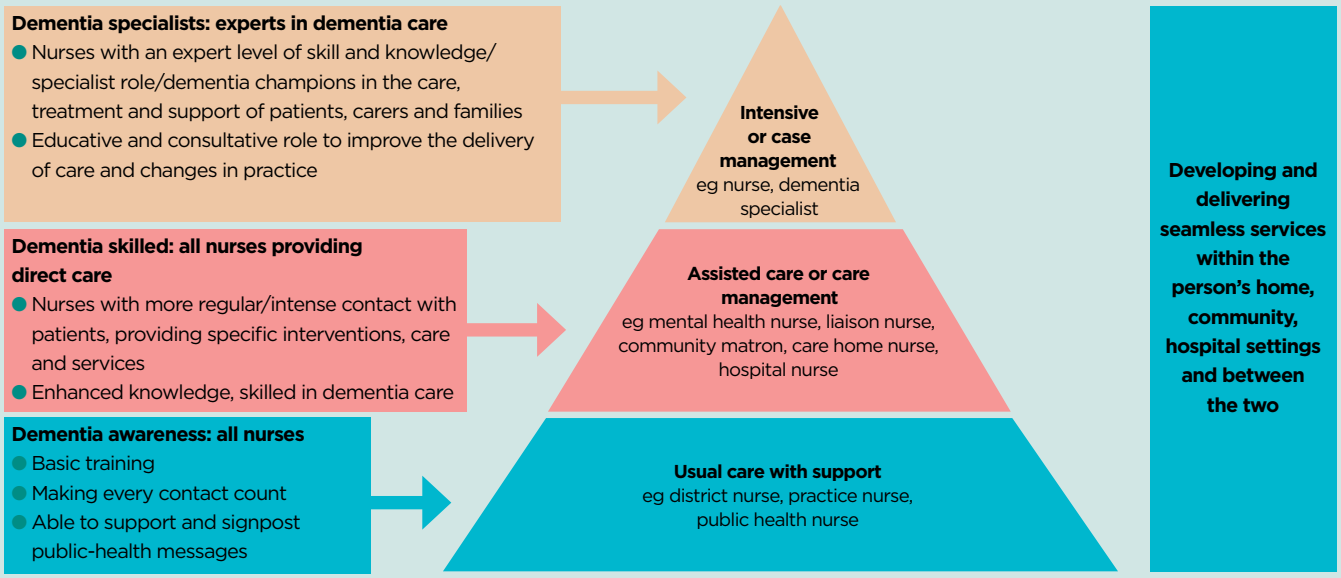
1. How could dementia nurse specialists improve care for people with dementia and their families?
2. Should specialist dementia care differ from, or be similar to, that provided by Admiral Nurses?
3. When in hospital, why are outcomes worse for people with dementia than for other patients?
4. Should dementia nurse specialists also have extensive legal knowledge of matters pertinent to patients with dementia and their families?
5. What changes should form part of the next national strategy for dementia care?

BOX 1. BENEFITS OF CLINICAL NURSE SPECIALISTS

- Care at reduced cost, eg through reduced admissions and inappropriate prescribing, improved value and increased efficiency
- System leadership and ability to facilitate service redesign
- Seamless, integrated, multidisciplinary care
- Experienced at treating the person, not the condition
- Excellent integrated person-centred care and experience (meeting key NHS clinical outcomes)
- Skilled at anticipatory care planning and continuity of care
- Able to make timely referrals to other specialist services

Adapted from: Read (2015)

FIG 1. **THREE LEVELS OF NURSING SERVICE PROVISION**



Source: Department of Health (2013)

diagnostic services, oncology and specialist nursing support (Independent Cancer Taskforce, 2015); it is recognised that more cancer CNSs are needed, as they have:

- Knowledge of, and insight into, the entire patient pathway;
- A high level of expertise in caring for people with cancer;
- Additional qualifications enabling them to perform advanced tasks, such as ordering and interpreting tests, conducting physical assessments, and prescribing medications.

CNSs have, in general, considerable knowledge of the healthcare organisation in which they work, and of partner organisations (Read, 2015); this is generally consistent with a three-level "cascade" model of training (Fig 1).

Dementia specialists

The DH (2013) says dementia specialists have "an expert level of skill and knowledge" and take on a specialist role or act as "dementia champions" in the care, treatment and support of people with dementia, their carers and families. Their educative and consultative role aims to improve the delivery of dementia services in practice.

Specialist nurses in other fields have yielded many benefits (Box 1) and their success overwhelmingly suggests an opportunity for specialists in dementia care to support their nursing colleagues and others in delivering high-quality, safe care in hospitals. Research is urgently needed to explore the perceived knowledge and competency of those specialist dementia care nurses who would not only be expected to possess higher levels of knowledge and skill than general nurses but are positioned as the obvious clinical group to engage with new ways of working (Page and Hope, 2013).

Admiral Nurses, as a prominent example of CNSs in dementia, have had a profound influence on policy development so far. Established as a result of the experiences of family carers, Admiral Nurses – named after Joseph Levy, who had vascular dementia and was known as Admiral Joe because of his interest in sailing – uniquely join the different parts of the health and social care system, and enable the needs of family carers and people with dementia to be addressed in a coordinated way (Box 2).

Many people compare the health and social care systems at all points from the disclosure of the diagnosis to "a labyrinth-like maze", and find the system difficult to navigate (Samsi and Manthorpe, 2014). The Admiral Nurse model was developed to enable people with dementia to:

- Stay at home and be better able to cope;
- Live more independently;
- Live more positively with dementia.

Admiral Nurses not only work with NHS organisations (primary, secondary, acute and community) to support families but also work in various other settings such as care homes, hospices and in the community supported by voluntary organisations. However, large numbers of people with dementia are admitted to hospital each year. Their needs are complex and their outcomes are found to be poor compared with patients who do not have dementia: delayed discharge and adverse events are common and costly, and they often report poor experiences of care (Royal College of Psychiatrists, 2013). Improved outcomes are already being witnessed where Admiral Nurses are employed within acute hospitals.

Why do we need dementia specialists?

A recent overview of the evidence, focusing on areas identified as important drivers of excess cost of hospital care, identified several ways in which dementia specialist nurses could have an impact, including direct patient care/consultancy on care of individuals, leadership and education (Royal College of Nursing, 2013). If specialist nurses reduced hospital stays by one day, on average, for each inpatient with dementia, the annual return on investment would be 37%, with a net saving of nearly £11m nationally (Griffiths et al, 2013).

While achieving clinically desirable outcomes – such as adding years to life and life to years – is a priority for the NHS, the service is strongly influenced by management accounting. The financial constraints on health and social care combined are well known, but the Admiral Nurse service greatly reduces the burden on both systems. An evaluation of an Admiral Nurse pilot in Norfolk identified savings of over £440,000 for health and social care in the area in just the first 10 months. Admiral Nurses reduced contact time of affected families with GPs, nurses and social workers, and avoided unnecessary hospital admissions and care home costs (Aldridge and Findlay, 2014).

The need for a CNS in dementia was

noted in the DH's (2009) English dementia strategy. Relevant priorities included:

- Raising awareness of dementia among staff in the acute general hospital (objective 1);
- Providing good-quality information for people with dementia and their carers (objective 3).

The specialist nurse professional role is much needed to match far better services to the needs of people living with dementia and carers: in particular, improving care for patients with the condition and, where appropriate, facilitating optimum end-of-life care for them (objectives 8 and 12) (Elliot and Adams, 2011).

Longstanding priorities in local and national policy and guidelines invariably now include:

- Expert guidance for other staff;
- Promoting choice and control in care.

The dementia strategy, and the CNS model in dementia, adopts a person-centred approach (Griffiths et al, 2015). This acknowledges that the wellbeing of people with dementia is highly dependent on the wellbeing of the people around them.

Caring for carers

Caring for a person with dementia affects the health and wellbeing of family carers. In the UK, government policy has increasingly highlighted the need to improve the lives of these carers and the current approach is for them to have access to a range of psychosocial and practical support. However, support available to carers is too often fragmented and inadequate.

A review of 155 studies of community-based support for carers of people with dementia concluded that they value specialist nursing support. However, the impact of such initiatives is not clear and more information is needed on the point in the dementia trajectory at which the contribution of specialist nurses can make a positive difference (Bunn et al, 2016).

Carers use a range of coping strategies to help them manage the demands of caring while sustaining their personal wellbeing, such as "looking at the bright side" or seeking support from others (Tschanz et al, 2013). Understanding these strategies is vital if the NHS and social care is to manage future demands on services, and has clear resource ramifications. The approach requires investment to safeguard the future of dementia care in England against funding threats.

The effectiveness of carers' coping strategies predict caregiver outcomes such as anxiety, depression and quality of life; they can ultimately influence whether the person with dementia needs to enter a residential care setting (Roche et al, 2016). The dynamics of the caring relationship between caregiver, care recipient and Admiral Nurse can be encompassed under an overarching process entitled "negotiating the balance" in taking decisions about care (Quinn et al, 2013).

The changes required in dementia care are profound. Delay in diagnosis and difficulty accessing appropriate healthcare services plague dementia care delivery in the community setting, leading to the risk of:

- Misdiagnosis;
- Inappropriate management;
- Poor psychological adjustment;
- Reduced coping capacity;
- Reduced ability to forward plan (Duane et al, 2015).

There is, currently, an appetite among members of the public to have a strong body of CNSs in dementia within the service provision (Rahman, 2015).

The best approach to care

Given the age profile of people with dementia, like many older people they are likely to be living with other long-term conditions. Person-centred care planning is ideal for such situations as it takes a holistic view of both met and unmet needs. Care plans are developed in consultation with the individual, family members, outside agencies and any other relevant parties (Skills For Care, 2015).

As pressure and demand on hospitals continues to rise, it is critical that dementia care in hospital be appropriate and of high quality. While some hospitals provide excellent care for such patients, all will find it challenging to provide and maintain good, person-centred dementia care as the number of these patients increases.

Admiral Nurses are well placed to address the needs of family carers and people with dementia in a coordinated way, which can result in a number of benefits, including a reduction in inappropriate antipsychotic prescribing. This is one major area of national policy that benefits from continuity of care. Prentice and Wright (2014) emphasised that nurses and carers in care homes for older people should always question whether antipsychotic therapy is really necessary – if it is, they should ensure the most appropriate drug is selected. Coordination of all services requires harmonised working from all regulated, trained professionals and practitioners. The Future Hospitals Commission, reporting to the Royal College of Physicians (2013), confirmed that:

"all patients deserve to receive safe, high-quality, sustainable care centred around their needs and delivered in an appropriate setting by respectful, compassionate, expert health professionals".

In the RCP (2013) model, a clinical coordination centre would form the operational "command centre" for hospital sites or medical divisions, including medical teams working in the community. It would:

- Provide staff with a valued resource through supervision, mentorship and modelling of good care;
- Hold detailed, real-time information on patients' care needs and clinical status;
- Coordinate staff and services so needs can be met.

CNSs would have a pivotal role.

Palliative care is offered to improve quality of life, and there is growing evidence that an early palliative care approach benefits people with any type of chronic life-limiting illness (Beernaert et al, 2015), including dementia. It can improve their quality of life and that of their families by preventing or relieving suffering through early identification, assessment and treatment of pain and other problems (World Health Organization, 2011).

The Mental Capacity Act has the potential to support the safeguarding and empowerment role of community nurses but nurse specialists providing support to carers and people with dementia may need greater familiarity with legal provisions. This would help them to:

- Provide general information;
- Make timely referrals to sources of specialist legal advice;
- Use the Act to reduce anxiety, conflict and disputes (Samsi et al, 2012).

Communication

Excellent dementia care is highly reliant on exceptional communication skills to involve patients in decisions. Failing to communicate when addressing the needs of a patient with dementia can often mean clinicians treat a collection of diseases rather than seeing the person. Dementia may cause some to appear quiet and withdrawn but appropriately skilled specialists could identify that they may actually be in pain or distress; staff trained in dealing with dementia – even when coping with the pressures of working on busy wards – are effectively these patients' advocates.

Jeni Bell was the UK's first hospital-based Admiral Nurse specialist, at University Hospital Southampton Foundation Trust. She shadows clinical staff and oversees a training and development programme that looks at understanding

BOX 2. THE ADMIRAL NURSES SERVICE APPROACH

- Focus on the needs of the whole family affected by dementia. This should include psychological support to help the person with dementia and family carers to understand and deal with their thoughts, feelings and behaviour, and adapt to the changing situation. Caregiving involves a change in ongoing patterns of exchange between the caregiver and care recipient. Both have to adjust to the transformation of their relationship into a caregiving one; this includes a change in the balance of roles as the caregiver takes more responsibility for the recipient's welfare. Admiral Nurses can offer expert input.
- Use a range of specialist interventions that help people with dementia to live well and develop skills that will help 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 times of difficulty in the dementia journey, such as diagnosis, when the condition progresses or when tough decisions need to be made, like moving 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, reduced coping capacity and ability to 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 work on the principle that family carers should be supported during the illness and into bereavement. The more social support they receive during the caregiving years, 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 the family's behalf. Such knowledge may help them with general matters, as opposed to solely medical ones (eg, further diagnosis and management of medical problems). For example, a nursing specialist could make timely referrals, if needed, to sources of specialist legal advice and use current legislation to reduce disputes.

patients' body language and how to handle those who do not interact verbally. She believes care could be transformed if nurses were given the opportunity to talk to patients as individuals rather than be restricted to purely medical interaction.

The way forward

Dementia UK works in partnership with NHS providers and commissioners, social care authorities and voluntary sector organisations to promote and develop new Admiral Nurse services. The charity is responsible for upholding standards, sustaining services and supporting Admiral Nurses in practice. In contrast with Macmillan Cancer Support or Marie Curie, but consistent the longstanding lack of parity with cancer services, the resources and political climate have not allowed specialist nursing in dementia to gain full recognition. This means the hundreds of thousands of people living with dementia in the UK and those who have a caring role, be it paid or unpaid, receive less support than those with cancer.

Nonetheless, with new models of care and intelligent commissioning of innovative services, people with dementia and their carers could see a service that is fit for purpose. The current offering from the NHS and social care is inadequate: we need to go far beyond mere awareness, important though that is. CNSs in dementia are desperately needed, and must be embedded in the country's next dementia strategy.

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