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Abstract: This report explores evidence to identify the potential benefits and to inform the implementation of dementia specialist nursing roles to support people with dementia during admission to hospital. It shows a business case exists for developing a dementia specialist nurse role in the United Kingdom. The evidence suggests that a properly trained and educated dementia specialist nurse, undertaking a clearly defined role, and working directly with people with dementia and their carers for a significant proportion of the time, could benefit people with dementia in hospitals. If these benefits addressed only a fraction of the excess stays experienced by people with dementia, a significant return on investment could be obtained. A reduction in hospital stay by one day on average could achieve an annual return on investment of 37%, with a net saving of nearly £11,000,000 nationally.

Scoping the role of the dementia nurse specialist in acute care

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Summary

Background

- Large numbers of people with dementia are admitted to hospital each year. Their needs are complex and their outcomes are poor compared to people without dementia.
- Delayed discharge and adverse events are common and costly. People with dementia and their families often have poor experiences of care.
- The success of specialist nurses in other fields suggests an opportunity for specialists in dementia care to support their nursing colleagues and others in delivering high quality and safe care in hospitals.
- The scale of the problem means the potential for improvement is great and the economic and social benefits of success are huge. The estimated additional costs of poor outcomes of hospital care for people with dementia are in excess of £250,000,000 per year.

UK Survey

- A survey of dementia specialist nurses working in the UK found a wide range of interpretations of the nurse specialist role, of activities undertaken by specialists, and of expected impacts.
- Expected impacts related to the development of other staff, successful and timely discharge, reduced use of anti-psychotic medications, and the prevention of adverse events including falls.

Evidence review: scoping

- Dementia specialist nurses can address many of the objectives of the United Kingdom governments' strategies for people with dementia admitted to acute hospitals.
- A model has been proposed that balances one-to-one support to people with dementia with wider practice development delivered by a dementia specialist nurse.
- Specific aspects of the role include addressing behaviour that challenges and discouraging inappropriate sedation; facilitating dementia training for other staff, based on a person centred approach; developing a dementia policy including pathways and screening tools for use by all hospital staff; and detailed care planning including activities of daily living.
- The potential return on investment from modest reductions in length of stay, with modest caseloads of patients, is high.
- The role remains untested and an evidence base to support development of an effective role needs to be closely scrutinised.

Evidence for effective interventions

An overview of evidence focusing on areas identified as important drivers of excess cost of hospital care and key challenges identified a number of ways in which dementia specialist nurses could have an impact. These include direct patient care/consultancy on care of individuals, leadership and education.

Direct patient care/consultancy on care of individuals

A clear role for dementia specialist nurses in direct patient care and consulting on the care of individual patients has emerged from this review. This includes the following activities:

- Enabling comprehensive assessment to identify patient and family carer needs, risk factors for adverse events during hospitalization and indicators of distress.
- Supporting colleagues and family carers in identifying and delivering individualized care strategies that optimize outcomes for individual patients and reduce their risk of adverse events and poor experiences.
- Providing care coordination and overseeing progress for people with dementia on inpatient wards, in emergency departments, in pre- and post-operative units and other acute settings in which people with dementia are cared for.
- Reviewing medication and ensuring timely referral to older peoples mental health liaison services.
- Initiating referrals for specialist diagnostic assessment.
- Supporting or undertaking discharge planning as part of a multidisciplinary team.
- Providing post-discharge follow-up and care coordination with community services.
- Providing the nursing input as a member of a specialist team.

Leadership

The review also identified that dementia nurse specialists could provide a leading role in initiating and facilitating the implementation of evidence-based interventions that optimise the outcomes for people with dementia across the hospital trust. These interventions include multidisciplinary programmes of care, strategies for case finding and screening for dementia, programmes focusing on patient safety such as falls prevention and on readmission reduction through redesigning care delivery.

Education

The review identified an educational role for dementia specialist nurse specialist in relation to the following activities:

- Lead the assessment of educational need across staff groups.
- Design, deliver and evaluate classroom-based and ward-based education.
- Lead the implementation of strategies such as dementia care mapping.
- Role model best practice to colleagues through collaboration and participation in patient care.
- Guide assessment of the effect of education and support change through audits of practice and individualized feedback.

Conclusions

- While there is little direct evidence, there is ample evidence that gives confidence that a dementia specialist nurse working in an acute setting could deliver substantial benefit for people with dementia and their family carers.
- There is a need to move beyond broad role descriptors to the design of a specific 'job' with therapeutic intent and a defined 'caseload'. The competencies and skills required should follow.
- The size of the patient population with dementia in many trusts means that it is unlikely that one person with a dementia remit can make a measurable difference for patients with dementia.
- Based on the caseloads described in the one detailed report available, we would suggest that to have a realistic chance of success there should be at least one whole time equivalent dementia specialist nurse for every 300 hospital admissions for people with dementia per year.
- Consideration needs to be given to the wide range of 'demands' on a specialist nurse and the potential that they are asked to do far too much to have any measurable benefit.
- Where specialists are required to give strategic leadership they need to be positioned and have the expertise, seniority and authority to do so.
- Strategic goals must be clear, the appropriate levers of action identified and the required structures must be in place to make success possible.
- The limitations of educational interventions need to be acknowledged, and the efforts of specialist nurses need to be targeted, so they can support behaviour change through role modelling and provision of targeted feedback on performance to others.

- Roles need to be developed in conjunction with existing stakeholders, resources and services to avoid isolation and duplication.
- The United Kingdom, unlike the USA, has a well-developed network of community health and social care services. Rather than direct follow-up with patients or family carers, it may well be that the key outreach activity is direct contact with community services to ensure successful handover.
- The existing capacity of the workforce to assume these roles is unclear. It seems likely that there will be a significant requirement for training.

Introduction

Dementia is a significant challenge and a key priority for the NHS. Each year, more than 900,000 people with dementia attend NHS hospitals in England alone and more than 150,000 spend an average of over 13 days in hospital – nearly three days longer than similar people without dementia [2]. It is estimated that at any one time up to 25% of beds in acute hospitals are occupied by people with dementia [3], with the figure likely to be considerably higher in some types of wards [4]. Discharge delays and adverse events are common [4]. People with dementia experience substantially longer hospital stays and require more nursing resources than similar patients without dementia [2, 4]. They are more likely to experience adverse events including dehydration, falls and malnutrition [2-4] and more likely to die or to be readmitted [2, 4, 5]. They are at risk of experiencing a loss of ability to care for themselves [3-5]. A conservative estimate of the additional costs to the NHS of these poor outcomes is over £250,000,000 per year [2], but this is likely to be a significant underestimate because dementia is often unrecognized or not recorded as a secondary diagnosis when people come into hospital [2].

In addition to the financial costs, the human costs are great. The experiences of care in hospitals for people with dementia are poor. A survey conducted by the Alzheimer's Society found that a majority of family carers reported significant negative effects on the physical or mental health of the person with dementia that was unrelated to the medical condition that led to admission. Seventy seven percent were dissatisfied with the overall quality of dementia care in hospital [3]. The national audit of dementia care in hospitals revealed significant shortcomings in both clinical and interpersonal care [6]. While high quality person-centred care can be found, it exists only in 'pockets' with variation between wards and between individual caregivers in wards [6] .

Part of the solution to this problem is to avoid unnecessary admissions [3, 7] but this does not remove the challenge of providing high quality care for people with dementia in hospital. While many admissions are for conditions that could be treated in the community with early intervention or the provision of alternative services, many are not[3]. People with dementia continue to have a right to acute care when the need arises. Their need for hospital care will continue to be significant as the population ages and the number of people with dementia rises [7].

The care delivered by nurses has been identified as being vital in supporting people with dementia and ensuring that the overall quality of hospital care is improved [3, 8]. Many of the negative experiences and outcomes are directly or indirectly linked to nursing care [9, 10] and, as part of a multidisciplinary team, nursing can contribute to improving these outcomes. However nurses face

real difficulty in rising to the challenge. The care of people with dementia is difficult and complex. Most nurses lack the specialist knowledge and skills required, and provision of education and training at all levels is, at best, variable [3, 6, 11]. Recent policies and guidance have recommended having a dementia clinical lead and a network of dementia "champions" in hospitals to support improvements in care [12, 13] but implementation is varied [6].

There is increasing interest in developing specialist nurse roles as part of the strategy to improve care of people with dementia. In 2011 the Royal College of Nursing facilitated a project designed to influence and guide the provision of dementia care in acute care settings[1]. As part of this work, surveys of practitioners, patients and carers indicated that the support of dementia specialists was seen as instrumental to supporting good quality care. Practitioners identified the importance of a clinical lead for dementia and support for education and training while 94% of people with dementia and carers indicated that having support from a dementia specialist was very important.

Specialist nurses have a long history of providing excellent care for people with a variety of long-term conditions[2]. For example, specialist nurses in cancer care work to provide improved coordination, communication, and to give emotional support and supportive interventions for symptoms. Patients in NHS trusts with more cancer nurse specialists report better experiences of care on a range of dimensions [15]. Specialist nurses have been associated with economic benefits [16] and work in a variety of ways to support care including direct care, consulting with other staff and supporting education and practice development [17].

Providing excellent care to people with dementia in hospital presents a significant challenge. The success of specialist nurses in other fields suggests an opportunity for specialists in dementia care to support their nursing colleagues and others in delivering high quality and safe care. Opportunities include improved care coordination and communication within the hospital team and with people with dementia and their carers. In this report we consider the potential impact of specialist nurses in supporting and improving the care of people with dementia. Because of the scale of the problem the potential for improvement is great and the economic and social benefits of success are considerable. The estimated additional costs of poor outcomes of hospital care for people with dementia are in excess of £250,000,000 per year.

[1] http://www.rcn.org.uk/development/practice/dementia/rcn_dementia_project

[2] While clearly codified in some countries, in the UK and elsewhere, terminology on advanced practice nursing roles remains ill-defined and inconsistently used (14.Bryant-Lukosius, D., et al., *Advanced practice nursing roles: development, implementation and evaluation.* Journal of Advanced Nursing, 2004. **48**(5): p. 519-529.). We use the term specialist nurse to encompass all nurses in advanced roles (e.g. Clinical Nurse Specialists, Nurse Practitioners, and Nurse Consultants) with a defined specialty.

- Large numbers of people with dementia are admitted to hospital each year. Their needs are complex and their outcomes are poor compared to people without dementia.
- Delayed discharge and adverse events are common and costly. People with dementia and their family carers often have poor experiences of care.
- The success of specialist nurses in other fields suggests an opportunity for specialists in dementia care to support their nursing colleagues and others in delivering high quality and safe care in hospitals.
- The scale of the problem means the potential for improvement is great and the economic and social benefits of success are huge. The estimated additional costs of poor outcomes of hospital care for people with dementia are in excess of £250,000,000 per year.

Survey of current roles

We undertook an online survey to explore the roles currently undertaken by specialist nurses in dementia[3]. 21,760 RCN members who had identified an interest in dementia, care of care of older people or mental health were approached. Dementia specialist nurses, those working primarily with people with dementia and those supporting people with dementia in a general hospital setting were invited to respond. Seventy-five nurses from across the UK whose job title indicated that they were specialist nurses working in an inpatient environment and who identified dementia care as the main or a substantial part of their role took part. Of these, 23 identified dementia as being the main part of their role. It is hard to judge if this is a representative sample or indicative of the number of specialist nurses working in hospitals with people with dementia because currently information is scant. However, survey results reflected a wide range of interpretations of the nurse specialist role, of activities undertaken by specialists and of expected impacts.

Respondents reflected that they held a range of qualifications. Many nurses held both RN and RMN qualifications, but only 42/75 had a BA degree and just 17 had a master's degree. Over half of respondents (41/75) identified direct patient care as the activity that occupied most of their time, although specialists whose main function was dementia more usually identified consultancy and / or education as the activities that took up most of their time (14/23). Under a third (24/75) spent the majority of time in a potentially more strategic leadership role. All respondents identified a role in educating other staff about dementia care and most participated in discharge planning for individual patients (60/75). Consultation covered a range of topics with physical environment, confusion/delirium and behaviour that challenges being the most frequently identified topics (all

[3] Full details of survey methods and findings are available in the technical appendix.

more than 60 / 75). Other activities that were common but far from universal included screening for cognitive impairment, providing therapeutic interventions for behaviour that challenges, advising on falls prevention, medication review, prescribing, and supporting ward based champions. Less than half the respondents identified that they led trust-wide developments in dementia care (32/75) and less than one third provided trust-wide strategic leadership on dementia care (23/75).

We asked respondents if they had been asked to demonstrate the impact of their role on a number of outcomes (Table 1). Responses may reflect a number of issues (including variation in the extent that activities have been evaluated) but do indicate the broad range of issues that specialist nurses may be expected to address, and both the challenge, and the opportunity for making a difference. Expected impacts relate to the development of other staff, successful and timely discharge, reduced use of anti-psychotic medications and the prevention of adverse events including falls and violent incidents.

Table 1: Impacts dementia specialist nurses had been asked to demonstrate

Impacts dementia specialist nurses had been asked to demonstrate	Dementia care a substantial part of role (n)	Dementia care main function of role (n)	All
Staff development	18	15	33
Discharge outcomes	21	11	32
Length of stay	20	11	31
Patient/Carer satisfaction	15	11	26
Use of anti-psychotic medication	13	12	25
Readmission rates	16	8	24
Falls	14	6	20
Pressure area care	8	2	10
Violent incidents	5	5	10
Grand Total	52	23	75

- Our survey of RCN members identified 75 specialist nurses working in an inpatient environment who identified dementia care as the main or a substantial part of their role.
- Survey results reflected a wide range of interpretations of the nurse specialist role, of activities undertaken by specialists and of expected impacts.
- Expected impacts relate to the development of other staff, successful and timely discharge, reduced use of anti-psychotic medications and the prevention of adverse events including falls and violent incidents.

Evidence review

The aim of this review is to analyse evidence in order to determine how nurse specialists could best be deployed to support people with dementia in acute hospitals. While we are aware that there are

specialist roles focusing on admission avoidance and facilitating primary/secondary care transitions, the focus of this review is solely on roles operating in acute hospitals in inpatient areas, emergency departments and/or theatres. Given the known under-diagnosis of people with dementia, the review was also designed to encompass interventions targeted at people with signs and symptoms of dementia, but not necessarily with a formal diagnosis.

The first stage of the review was informed by ethnographic principles. A wide net was cast across the considerable body of potentially relevant published literature to present an overview of the amount and quality of the evidence, derive topics for further systematic investigation and present a body of literature against which the findings of the more formal searches could be validated. Following on from this general scoping review, more systematic searches were carried out to identify publications at the top of the hierarchy of evidence on a specific set of outcomes related to the potential impact of the dementia specialist nursing role in hospitals. These searches focussed on the three core cost drivers of excess cost for hospital stays in a recent analysis of hospital admissions for people with dementia [2]:

- Falls
- Length of stay
- Readmissions

In addition we searched for evidence in other areas that might be affected by nurse specialist inputs including:

- Screening, diagnosis and assessment
- Pressure ulcers
- Delirium
- Agitation and behavioural symptoms of dementia
- Behaviour, knowledge and attitudes of non-specialist staff (including nursing and medical staff)
- Patient and carer reported outcomes (quality of life and experiences of care)

Details of the full search strategy can be found in the technical appendix.

Scoping review

There is a considerable body of literature on the development of nursing skills and competencies in caring for people with dementia. These publications rarely specifically address the care setting and where they do they tend to focus on care homes. Most concern the skills required by any nurse

working with older people. The competency framework developed for the "Admiral" specialist dementia nurses [18] provides a broad framework:

- Therapeutic work (interventions)
- Sharing information about dementia and carer issues
- Advanced assessment skills
- Prioritizing work load
- Preventative and health promotion
- Ethical and person centred care
- Balancing the needs of the carer and the person with dementia
- Promoting best practice

The published framework does little to elucidate the skills required for work in an inpatient setting, although additional training materials are available to Admiral Nurses.

A number of publications specifically address the work of Admiral Nurses or other dementia specialist nurses working in community or primary care [18]. Several address dementia specialist nurses working in care homes. Most of these papers are descriptive, although in a small number of cases, they evaluate the impact of the role. While we are aware that some Admiral Nurses are deployed in acute hospitals in England (for example at University Hospital Southampton) and Alzheimer's Scotland are supporting the deployment of specialist nurses in acute hospitals, we found no evaluations of these initiatives.

A single empirical study reports on and evaluates the role of a dementia specialist nurse in an acute hospital setting [19]. The role was shaped around several objectives of the National Dementia Strategy [20]. Priorities included raising awareness of dementia among staff (Objective 1) and providing good quality information for people with dementia and their family carers (Objective 3), improving inpatient care for patients with the condition and, where appropriate, facilitating optimum end-of-life care for them (Objectives 8 and 12). The role is described as being based on a 'Person-Centred' approach; that is valuing people with dementia and treating them as individuals, looking at the world from the perspective of the person with dementia, and recognizing that people with dementia need an enriched social environment [21]. Specific aspects of the role described include addressing behaviour that challenges and discouraging inappropriate sedation, facilitating dementia training for other staff based on a person centred approach, developing a dementia policy including pathways and screening tools for use by all hospital staff, detailed care planning including all the activities of daily living based on recommendations from the Alzheimer's Society [3],

consultation on dementia specific pain assessment, and screening for delirium and depression. A role in admission avoidance through providing consultation and assessment on patients in accident and emergency is also described.

The role was delivered by a single nurse in a 538 bed hospital who screened 20 new cases per month and provided on-going support to an average of 18 patients through daily follow-up in the hospital. The authors estimate that 720 bed days per year were potentially saved by the introduction of the dementia specialist nurse [19] based on a reduction of average stay from 11 to 9 days, although the empirical basis of this claim is unclear in the report. Using the 2011 average NHS excess day tariff (£231 per day, as used by CHKS in their report [2]) this saving in bed days equates to a cost saving of over £150,000 set against a total salary and pension cost likely to be less than £75,000[4] for employing a very senior and experienced specialist nurse (band 8C) or £45,000 at band 7 [19].

The potential for both patient benefit and cost saving from this role seems clear. However, the evidence from this single evaluation is weak. The scoping review identified many publications on the development of services for people with dementia in acute hospital settings. This literature describes and evaluates interventions designed to improve hospital based services for people with dementia in some way. Interventions include both whole system approaches aimed at bringing about overall service improvements and specific initiatives, such as the introduction of a single tool or device aimed at addressing a specific element of practice. These publications do not generally identify a specific role for a dementia specialist nurse although specialist nurses are often involved in delivering interventions. Although not yet reported in the peer reviewed literature, the evaluation of a service development that includes a specialist ward and outreach team for people with dementia, including two specialist nurses, is a current UK example of developments[22]. A number of publications assess the potential and/or actual impact of interventions which Elliot and Adams have demonstrated can effectively be incorporated into a dementia specialist nurse role, such as training for ward staff, policy and pathway development, implementation of assessment, diagnosis and screening tools [19]. These will be reviewed later.

The remainder of this report reviews research literature in more detail in relation to specific interventions and outcomes relevant to the dementia specialist nurse role, focussing on studies which provide evidence for the potential effectiveness of such a role.

[4] Band 8C point 43 2012 salary £58,431 + NI and superannuation. Band 7 point 30 2012 salary £35,184 431 + NI and superannuation.

- Dementia specialist nurses can address many of the objectives of the national Dementia Strategy for people with dementia admitted to acute hospitals.
- A model has been proposed that balances one-to-one support to people with dementia with wider practice development delivered by a dementia specialist nurse.
- The potential return on investment from modest reductions in length of stay with modest caseloads of patients is high.
- The role remains untested and an evidence base to support development of an effective role needs to be closely scrutinised.

Falls

People with dementia are more likely to fall in hospital than people without dementia. Overall, people with dementia are more than twice as likely to experience an adverse event while in hospital than those without, with falls being by far the most commonly recorded [23]. When they fall they suffer potentially life threatening injury, experience substantially longer hospital stays and experience more time at risk of other adverse events including malnutrition and pressure ulcers [2]. The cost of extended hospital stays due to falls among people with a recorded diagnosis of dementia is conservatively estimated at £25,000,000 per year [2]. This is likely to be an underestimate as many people are undiagnosed or do not have their diagnosis recorded in the hospital record. The costs of treating fall-related injury or subsequent complications are also not included.

There is a substantial evidence base on falls prevention in hospitals, care homes and the community which is reported in a number of high quality systematic reviews [24-27]. The evidence for simple single strategies for fall prevention in hospital (such routine use of a falls risk assessment) is weak, whereas there is support for multifactorial interventions where an individual's risk is assessed and interventions targeted to their need. Evidence suggests that the rate of falls can be reduced by over 30% although evidence on a reduction of the risk of falling at all is less clear [27]. Effective interventions combine some or all of the following: exercise, medication review, management of urinary incontinence, fluid or nutritional therapy, environmental change or assistive technology and changes to the social environment. One systematic review found no overall significant association between dementia or cognitive impairment and the impact of strategies to prevent falls or fractures in care homes and hospital [25] although some otherwise effective strategies appear to be ineffective in people with cognitive impairment [28]. Conversely some effective strategies seem to most benefit those whose stays in hospital are longer [29].

Thus it seems likely that a reduction in falls among people with dementia in hospital is achievable. Prevention requires strategies that are tailored to the individual risk factors of the person with

dementia. It is likely that some of these will be directly related to dementia (for example wandering or confusion). Otherwise effective strategies need to be adapted for use with people with dementia.

A dementia specialist nurse could:

- Undertake individual risk assessments and plan / implement a tailored prevention strategy, based on best evidence
- Reduce risk by delivering support for specific dementia-related risk factors
- Advise on dementia-specific factors to be considered in broader strategies

Length of Stay

People with dementia are likely to stay longer in hospital. Overall, people with dementia stay in hospital on average 25% longer, and in some places 85% longer, than people without dementia [2]. Dementia is associated with older age, poorer nutrition, poorer functional ability and increased risk of delirium and falls. All these factors can predispose individuals to a longer length of stay [4] and increase the demand for specialist input and effective care coordination. Excess length of stay by people with dementia is estimated to cost the NHS £120,000,000 annually [2], but this is likely to be an underestimate that only reflects patients with a known and documented diagnosis of dementia.

Cochrane systematic review findings indicate that nurse specialist roles (not specific to dementia) can make a contribution to reducing length of hospital stay for hospitalised patients [30]. The review included studies on the impact of masters-prepared specialist nursing roles focused on the needs of specific patient groups, such as patients with diabetes or multiple sclerosis. Roles commonly involved care coordination activities such as arranging tests and procedures, patient assessment, care planning, progress review, undertaking or prescribing specific interventions based on assessed needs, and educating patients, nurses, and other staff. Results from a further systematic review that included studies on the impact of gerontological nurse practitioners, including community-based roles, suggest that such roles can help reduce length of stay [31].

A number of primary studies indicate a clear contribution by specialist nursing to interdisciplinary interventions shown to be effective in reducing length of stay. These interventions include a clinical pathway for people with dementia[32], a psychiatric and geriatric consultation service [33] and an Acute Care for Elders (ACE) inpatient team [34]. The clinical pathway evaluated by Kazui and colleagues specified the following role for nurses: assessing cognitive impairment, behavioural and psychological symptoms of dementia, neurological deficits and activities of daily living in the hospital. The nursing role also included identification of effective management strategies for behavioural and psychological symptoms, and functional disabilities, as well as teaching these to caregivers. [32]

A dementia specialist nurse could:

- Provide comprehensive assessment and care coordination
- Oversee the delivery of inpatient care and progress review tailored to individual care needs and focused on reducing individual risk of adverse events
- Support other caregivers (including family carers) in identifying and delivering management strategies
- Support or undertake discharge planning as part of a multidisciplinary team

Readmissions

Compared to people in hospital without dementia, the rate of readmission within 30 days for people with dementia is nearly 1.5 times higher following an unplanned admission, and more than twice as high following a planned admission [2]. The annual cost of readmissions of people with dementia is conservatively estimated at £120,000,000 [2]. For those with a recorded diagnosis of dementia there are more than 35,000 unplanned readmissions per year, with an estimated cost of £110,000,000 incurred because of additional hospital stays alone.

A number of studies provide evidence about the positive impact on readmission of interventions delivered by nurses, including nurse specialists, which have implications for the potential role of a dementia specialist nurse. Most centre around ways of organising services for older people such as care management, liaison nurses, multidisciplinary approaches and discharge planning, although many studies have explicitly excluded older people with dementia and few report on them separately [35-40]. Modest reductions in readmission are associated with discharge planning in a Cochrane systematic review [35] although the role of nurses in the interventions was not always clear and a systematic review of nurse staffing models found no evidence for a positive effect on readmissions from the addition of specialist nurses to the nursing team in general [30].

The advanced practice nurse transitional care model, in which experienced masters-prepared specialist nurses undertake discharge planning and coordinate care across the transition from hospital to home, has been extensively tested in the US with strong evidence from trials to support reduced readmissions and costs for some groups of older patients [41]. While outcomes have not yet been reported this approach has been piloted and tested with cognitively impaired older adults [42-44] with a trial due to report shortly. The strategies integrated into the interventions include screening and early detection of dementia, delirium and depression; prevention of adverse clinical events such as falls, drug interactions, incontinence; prevention of delirium; multi-dimensional intervention (education, support, reorientation); medication reviews; use of protocols and guidelines;

and tailoring interventions to meet the needs of the patients and caregivers. Post-discharge follow-up is an important part of this intervention although the context of care and availability of community services in the UK may provide opportunities to deliver this function in other ways.

A dementia specialist nurse could:

- Provide comprehensive assessment and care coordination
- Support or undertake discharge planning as part of a multidisciplinary team
- Reduce readmissions by redesigning care delivery and implementing evidence based programmes
- Provide post-discharge follow-up and care coordination with community services

Other adverse events

In addition to the three major cost drivers of length of stay, falls and readmissions that were identified in the CHKS report [2], people with dementia are vulnerable to other physical and psychological problems whilst in hospital – some of which are related to dementia and some of which are general. Cognitive impairment is identified as a trigger event in so called 'cascade iatrogenesis' [45], the serial development of multiple medical complications that can be set in motion by a seemingly innocuous first event [46]. These complications include delirium, infection, pressure ulcers and post-operative respiratory complications.

No publications directly addressed the role of a dementia specialist nurse in preventing or treating such complications in acute settings. There is evidence from a recent quality randomised trial that in general hospital settings, multiple risks (pressure ulcers, infection and falls) can be targeted through a multifaceted education and performance feedback programme that also involves patients [47]. Inouye and colleagues found that a nursing education programme in a hospital setting resulted in a beneficial effect, preventing or reducing functional decline in frail older patients with one of four geriatric target conditions at baseline (delirium, functional impairment, incontinence, and pressure ulcers)[48]. In a controlled before and after study, specialist gerontological nurses worked with staff in care homes to implement scientifically based protocols leading to reductions in pressure ulcers, depression, and aggressive behaviour [49].

Evidence for the effectiveness of non-pharmacological interventions for cognitive, behavioral, psychological and depressive symptoms of dementia is lacking [50] but there is clear evidence that potentially harmful antipsychotic medication used for behavior that challenges is not always in accord with guidance, which identifies this as a last resort [6]. Assessments frequently fail to identify

behaviours which might be early indicators of distress and so opportunities to avoid problems are missed [6]. Access to liaison psychiatry is often not timely [6].

While substantive evidence is lacking, there is a clear body of expertise relating to strategies for communicating with people with dementia [51-53] aimed at 'avoidance of adverse events' [54], including in patients attending the emergency department [54]. Similarly there are numerous aspects of environmental design that are likely to improve the experience of older people and reduce the risk of both physical and psychological adverse events [55].

A dementia specialist nurse could:

- Support the dissemination and implementation of best practice in avoiding harm
- Enhance assessment and identify dementia specific risk factors and individual indicators of distress
- Give specific support, consultation and assessment in settings including A&E and pre and post-operative units
- Review medication and ensure timely referral to liaison psychiatry services

Screening and Diagnosis

In order to target care and improve outcomes dementia must be recognised. Even after hospital admission, detection rates are low (37–46%) and dementia is often missed [4, 56, 57]. National strategies aim to remedy this. For example, in England the dementia targets in the Commissioning for Quality Improvement (CQUIN) incentivise trusts to screen, and where appropriate assess and refer, all patients over 75 admitted to hospital [58]. In Wales the 100 lives+ strategy identifies a similar screening and assessment strategy for people admitted to Welsh hospitals [59]. The specificity of the single CQUIN screening question is likely to be poor and, since many people under 75 also have dementia, it will not in itself resolve the problem of identifying people with dementia.

There is very limited published evidence that directly addresses the role of dementia specialist nurses in relation to screening, assessment and diagnosis in acute care. Extensive searching of the databases of peer-reviewed publications found no systematic reviews or clinical trials. Screening is described as part of the role in the single evaluation that we found [19]. If support is to be targeted, screening is required, followed where appropriate by further diagnostic assessment. There is a significant potential role for specialist nurses in this although, unless there is further action to support care, benefits are unlikely to accrue during the hospital stay.

One systematic review addressed screening, diagnosis and assessment in patients with dementia presenting in A&E but found no empirical studies. The use of standard cognitive screening by emergency nurses as a strategy for recognizing dementia in the Emergency Department is recommended [60], as is assessment of delirium [51]. One review identified a tool recommended for nurse administration [61]. A Geriatric Nursing Education Course has been shown to increase self-reported use of a cognitive assessment tool and an improvement in ability to screen for depression and dementia in a controlled before and after study [62].

There is evidence that appropriately trained specialist nurses can reliably identify and stage dementia using standardised instruments [63, 64]. Other more comprehensive interventions to support older people in hospital, such as the Hospitalised Elder Life Programme use specialist nurses to assess multiple risk factors, including cognitive impairment [65, 66].

A dementia specialist nurse could

- Support hospital wide strategies for case finding and screening
- Provide further detailed assessments
- Initiate referrals for specialist diagnostic assessment

Models of care

People with dementia who are admitted to hospital are likely to have complex needs, which may be unrelated to the primary presenting condition, that need proper assessment and intervention to ensure optimal outcomes. These needs include nutrition, hydration and help with washing and dressing which are often unrecognised and unmet [3, 4]. Disorientation and delirium are common [4, 67], and often associated with agitation, distress and behaviours that staff find challenging as well substantial morbidity [67]. In addition, the assessment and management of symptoms associated with the presenting condition, or other comorbidities, can become more complex because of cognitive impairment and communication difficulties. For example, pain can be difficult to assess and there is evidence that people with dementia may be given far less post-operative pain medication than others who have experienced the same painful procedures [68]. Approaches to assessment and intervention may be comprehensive in nature, with a focus on domains beyond the primary presenting condition; and multi-faceted, requiring multidisciplinary input and a focus on care coordination or case management.

A number of models of care targeted at people with dementia in hospital, or at hospitalised older people, have been identified through the review and are summarised here, as they could inform the

development of dementia specialist nurse roles and strategies, although there is no evidence for the specific impact of dementia specialist roles within these interventions.

Specialised care units and specialist consultation teams have been associated with improved care for older people in hospital. One review identified eight different specialised care units for older people that commonly included interdisciplinary specialised geriatric resources on designated units [69]. None were focused on patients with dementia, although the Hospital Elder Life Program (HELP) is aimed at reducing delirium in hospitalized older adults.

HELP's intervention strategy includes a skilled interdisciplinary team, highly trained and supervised volunteer staff, interdisciplinary geriatric assessment and the delivery of standardized protocols. There is moderate evidence, from a non-randomised controlled trial and two before and after studies, for lower rates of delirium and functional decline with HELP in a range of acute patient populations [65, 70, 71]. The intervention was not specifically targeted at those with dementia although a subgroup analysis showed significant improvement in the degree of cognitive impairment among patients with impairment at admission [70].

The scoping review cited above [69] identified a range of specialised consultation teams for older hospitalised adults, including one led by a geriatrician trained in geriatric psychiatry and including a specialised geriatric liaison nurse. The team focused on providing psychogeriatric liaison for medical patients. A single randomised controlled trial showed a beneficial effect on physical functioning, length of stay, readmissions and nursing home placements [33]. A Cochrane systematic review on comprehensive geriatric assessment (CGA) for older hospital patients admitted as an emergency conclude that CGA increases a patient's likelihood of being alive and in their own home at up to 12 months [36], but only two of the 22 included trials evaluated CGA for patients with dementia [72, 73].

In general hospital settings dementia care mapping (DCM), a care improvement process to enhance person-centred care for people with dementia has been shown to be feasible [74]. There is some evidence to support its efficacy in long-term care settings however, its impact on patient outcomes in acute settings has not yet been established. Other models of care that could inform the development of nurse-led acute care strategies for people with dementia, but for which there is little or no evidence of effectiveness for this patient group, include Nurses Improving Care for Health-System Elders (NICHE)[75], Progressively Lowered Stress Threshold (PLST) [76], and Creating Avenues for Relative Empowerment (CARE) [77].

A dementia specialist nurse could:

- Lead the development and implementation of multidisciplinary programmes of care
- Provide the nursing input as a member of a specialist team

Developing the skills of non-specialist staff

The care of people with dementia is difficult and complex. Most nurses and care staff lack the specialist knowledge and skills required, and provision of education training at all levels is, at best, variable [3, 6, 11, 78, 79]. Recent policies and guidance have recommended having a network of dementia "champions" in hospitals to support improvements in care [12, 13] but implementation is varied [6]. Training is required at all levels – from basic awareness training for the majority of staff who come into contact with people with dementia through to more comprehensive training for qualified staff and others who frequently provide care, including the prospective 'champions'.

A major skills and knowledge gap in acute care for people with dementia among registered nurses and care assistants is widely recognised and several learning resources exist (e.g. NHS Scotland, The Alzheimer's Society and the RCN). However, remarkably little high quality evidence is available to guide the further development of such programmes, optimise delivery or identify the role that nurse specialists could take in these developments. Successful education is a prerequisite for delivery of some of the effective programmes that are outlined elsewhere in this report. The relevant evaluations that have taken place have largely focused on dementia care education for care home staff and its impact on staff-reported outcomes.

Features of educational interventions that are described in the literature and that may be relevant to the educational aspects of dementia specialist nurses' role include designing an educational plan based on assessment of a (primary care) team's educational needs [80]; the use of strategies such as dementia care mapping [81]; practice-based education and role modelling [82, 83]; and the inclusion in training programmes of content related to communication strategies, management of disturbing behaviours, focusing on resident/patient abilities, caregiver involvement, patient safety, advocacy, pain management and ethics [51, 60, 84-86]. However the evidence base for these features is mostly weak. Two systematic reviews indicate that educational interventions that are strongly theoretically based, multi-faceted, of sufficient intensity and duration, and supplemented by additional supervision and sufficient management support, may deliver the best outcomes, while concluding that the evidence base is weak [87, 88]. Tailored feedback on performance is supported by a high quality systematic review as a strategy that leads to change in professional behavior and patient outcomes [89].

A dementia specialist nurse could:

- Lead the assessment of educational need across staff groups
- Design, deliver and evaluate classroom-based and ward-based education
- Lead the implementation of strategies such as dementia care mapping
- Role model best practice to colleagues through collaboration and participation in patient care
- Guide assessment of the effect of education and support change through audits of practice and individualized feedback

Discussion

Problems in the quality of acute hospital care for people with dementia are well documented, and a variety of policy drivers are now providing the impetus for service improvements. We are aware that many trusts are making improvements to services provided to people with dementia (e.g. the Butterfly scheme, "This is me" booklet" and improvements in physical environment) but have focused our review on robust evidence of measurable effect. As the survey results reflect, specialist nurses are already engaged in some acute hospitals and it is probable that many other organisations will now seek to fund such posts. In conducting this review, we sought evidence that could guide the development of these roles.

There is little direct evidence because this is a new role. There is however, ample evidence that gives confidence that a dementia specialist nurse working in an acute setting could deliver substantial benefit for people with dementia and their family carers. To deliver these benefits the role needs to be carefully designed, the post holder needs to be properly trained and have sufficient skills. They must draw on existing mechanisms and interventions known to have a beneficial effect in improving patient and family experiences, optimising patient outcomes including reducing length of stay and preventing adverse events such as falls and readmissions.

Caseload

We must be mindful of the potential wide range of 'demands' on a nurse specialist and the potential that they are asked to do far too much to have any measurable benefit. Where they are required to give strategic leadership they need to be positioned, and have authority and links to do so. Their reduced capacity to deliver one-to-one patient care must be explicitly recognised. Strategic goals must be clear, the appropriate levers of action identified and the required structures must be in place to make success possible. The limitations of educational interventions need to be

acknowledged and the efforts of specialist nurses need to be targeted so they can support behaviour change through role modelling and provision of targeted feedback on performance to others.

The size of the patient population with dementia in many trusts means that it is unlikely that one person with a dementia remit can make a measurable difference to all dementia patients, unless the role is focused on facilitating the adoption of evidence-based strategies in staff groups across the trust. However, while the survey findings reflected that all respondents had an educational remit, less than one third provided strategic trust-wide leadership in dementia care.

A clear balance needs to be struck between the benefits to individual patients with dementia and their carers from the direct involvement of a specialist in their care, and the need for whole organisations to shift their thinking and practice to more dementia-friendly ways. It may be that most organisations need more than one dementia specialist nurse. Careful consideration needs to be given to the "nurse dose" required to have an effect [90]. Essentially, nurse dose refers to the amount of specialist nurse time available across the range of expected activities and demands. If the "dose" is insufficient it is unlikely to have any effect. Alzheimer's Scotland gives a target case load of 250 patients per year[5]. Based on the caseloads described in the one detailed report available [19] we would suggest that to have a realistic chance of success there should be at least one whole time equivalent dementia specialist nurse for every 300 annual hospital admissions of people with dementia per year. However this does not take into account a significant increase in rates of assessment and screening work that could be triggered by the introduction of routine screening. The evidence base clearly demonstrates that much of the benefit for patients is from the direct work with people with dementia that results from active identification of cases. If cases are identified but no change in care results, little has been achieved.

Developing roles

While the need for support and potential roles of specialist nurses extend across traditional boundaries (hospital and community, health and social care), an acute admission is a critical threat to the health and well-being of people with dementia. The need for intensive support to prevent significant harm is analogous to the provision of intensive care for critical illness. To deliver on the promised benefits specialist nurses need to be able to focus their efforts while working closely with the wider multidisciplinary team. To have maximum impact a dementia specialist nurse in acute hospitals needs to coordinate their efforts and integrate their service with existing service, both in the hospital and community. The issue of post-discharge follow-up, crucial to the success of the

[5] https://secure.thebiggive.org.uk/projects/view/3939

transitional care model, needs careful consideration. Unlike in the USA, the United Kingdom has a well-developed network of community health and social care services. Rather than direct follow-up with patients or family carers, the key outreach activity could be direct contact with community services to ensure successful handover.

To avoid isolation and duplication, roles should be developed in conjunction with stakeholders, taking account of available resources and services. Medicine and psychiatry for older people, and existing liaison services, are crucial resources with considerable relevant expertise, as are managers of specialist older people's wards. Embedding specialist nurses within these existing teams may be beneficial. However, to expand and enhance the care offered to people with dementia in hospital, they should offer a service that is new and distinctive, rather than simply replicate, or substitute for, the work of others.

It will be important to be mindful of lessons learned from the implementation of advanced practice nursing roles, including nurse consultants in the UK. Bryant-Lukosius summarised the issues nearly ten years ago [14], although we should not assume that lessons have been learned. Organizations often initiate new roles as a solution to a specific health care issue but do not set well-defined achievable goals based on a systematic needs assessment and clear understanding of the evidence base for what is feasible and effective. Organizations fail to define new roles and how they will achieve priorities for improving health care. In the absence of clear or realistic goals, roles become shaped by the expectations of stakeholders such as managers and nurses in the role, resulting in wide variations in how roles are interpreted and used. Lack of role clarity and inconsistent expectations contribute to problems such as role conflict, role overload, and variable stakeholder acceptance. Inexperience with nurses working in advanced roles by those involved in introducing the roles, can lead to misinterpretation and under-use of the role [14].

Competencies and skills

We identified little specific evidence regarding what personal characteristics and competencies are required in a dementia specialist nurse role, although broad frameworks do exist. In the USA and Canada, and in some NHS trusts, masters preparation is required for a clinical nurse specialist role, but the survey findings reflect that a relatively small proportion of existing dementia specialist nurses are qualified to this level. In addition, where educational level is specified in the interventions evaluated, masters-prepared nurses commonly feature. The evidence demonstrates that advanced knowledge and skills are required to carry out specialist roles in interventions targeted at hospitalised frail older people. We can assume that the same applies for specialist roles in dementia care. This evidence also points toward a specific set of knowledge and skills that are

required. There is a need to move beyond broad role descriptors to the design of a specific 'job' with therapeutic intent and a defined 'caseload'. The competencies and skills required should follow.

There is room for diverse roles to be developed, based on local needs. They are likely to divide between those that are primarily strategic and educational, focussing on organisational development, and those focussed on care delivery and one to one support for patients and staff. In both cases attention should be directed towards designing and delivering services of known, or likely, effect. Those taking on strategic leadership roles must have sufficient seniority, experience and credibility to do so.

The existing capacity of the workforce to assume these roles is unclear. It seems likely that there will be a significant requirement for training. Universal implementation in a short period of time risks embedding post holders without the required experience or skill. A more progressive implementation is recommended with a gradual increase in capacity and a move from focussed to more universal coverage over a period of 5 years. Gradual implementation, reflecting the diversity of local needs and existing capacity, also creates the opportunity to evaluate what is, at the moment, an untested approach to delivering support. Implementation, either locally or nationally, needs to consider the availability of routine data for evaluation and the potential for rigorous research through cluster randomised controlled trials or observational studies based on 'natural experiments.

Business case

We believe that a business case exists for developing a dementia specialist nurse role in the United Kingdom. There is reason to suppose that a properly trained and educated dementia specialist nurse undertaking a clearly defined role and working directly with people with dementia and their family carers for a significant proportion of the time could benefit people with dementia in hospitals in a number of different ways. If these benefits addressed only a fraction of the excess stays experienced, significant return on investment could be obtained. In Box 1 we present a simple scenario in which a single grade of specialist is employed at band 7. In this scenario, if dementia specialist nurses with a caseload of 300 patients per year were able to reduce hospital stay for older people by one day on average, an annual return on investment of 37% could be achieved by training and employing 583 specialists for England. Numbers for Northern Ireland, Scotland and Wales could be modelled in the same way using local data on admissions. Other scenarios could be envisaged where a team of specialists at different grades were employed within one trust, provided that suitable senior clinical leadership (potentially at band 8 nurse consultant level) is present to support more junior specialists and all staff are properly trained. Additionally to these roles, there is potential for senior strategic clinical leaders at nurse consultant level to support and further develop care standards across the

organisation, bridging boundaries between professional groups and provider sectors. Their remit and success criteria will need to be clearly and carefully defined in terms of clinical, professional and organisational impacts. For them to succeed they need to have significant expertise, seniority and authority and to work closely with senior colleagues from other disciplines.

Box 1: Potential return on investment in dementia specialist nurses[6]

Dementia specialist nurse employed at band 7: annual cost	£45,000[7]
Annual number of 'cases' per specialist nurse	300
Number of specialist nurses required	583
Annual training costs[8]	**£ 3,206,500**
Annual salary costs	**£26,250,000**
Number of hospital stays [9]	175000
Number average 'excess' stay	2.9 days
Reduction in excess stay	1 day
Cost per day	£231
Savings from reduced length of stay	£ **40,448,100**
Net annual savings	**£ 10,991,629**
Return on investment	**37%**

Concluding Summary

- While there is little direct evidence, there is ample evidence that gives confidence that a dementia specialist nurse working in an acute setting could deliver substantial benefit for people with dementia and their family carers.
- There is a need to move beyond broad role descriptors to the design of a specific 'job' with therapeutic intent and a defined 'caseload'. The competencies and skills required should follow.
- The size of the patient population with dementia in many trusts means that it is unlikely that one person with a dementia remit can make a measurable difference to all dementia patients.
- Based on the caseloads described in the one detailed report available we would suggest that to have a realistic chance of success there should be at least one whole time equivalent

[6] The data used here are based on Investment and savings for England only. Additional investment would be required and savings generated for other UK countries

[7] Data from NHS employers – mid-point band 7 + 25% for NI and superannuation

[8] Assumes a training cost of £5000, replacement costs by a band 6 practitioner and 20% staff turnover per year

[9] Hospital stays, excess stays and cost per day calculated using data / assumptions from CHKS for England only

2. CHKS, *An economic analysis of the excess costs for acute care for patients with dementia*. 2012, Report to Dementia Challenge Working Group.

dementia specialist nurse for every 300 hospital admissions for people with dementia per year.

- Consideration needs to be given to the wide range of 'demands' on a specialist nurse and the potential that they are asked to do far too much to have any measurable benefit.
- Where they are required to give strategic leadership they need to be positioned and have the expertise, seniority and authority to do so.
- Strategic goals must be clear, the appropriate levers of action identified and the required structures must be in place to make success possible.
- The limitations of educational interventions need to be acknowledged and the efforts of specialist nurses need to be targeted so they can support behaviour change through role modelling and provision of targeted feedback on performance to others.
- Roles need to be developed in conjunction with existing stakeholders, resources and services to avoid isolation and duplication.
- Unlike in the USA, the United Kingdom has a well-developed network of community health and social care services. Rather than direct follow-up with patients or family carers, it may well be that the key outreach activity is direct contact with community services to ensure handover is successful.
- The existing capacity of the workforce to assume these roles is unclear. It seems likely that there will be a significant requirement for training.
- Implementation, either locally or nationally, needs to consider the availability of routine data for evaluation and the opportunity for rigorous research through cluster randomised controlled trials or observational studies based on natural experiments.
- We believe that a business case exists for developing a dementia specialist nurse role in the United Kingdom. There is reason to suppose that a properly trained and educated dementia specialist nurse undertaking a clearly defined role and working directly with people with dementia and their family carers for a significant proportion of the time could benefit people with dementia in hospitals in a number of different ways.
- If these benefits addressed only a fraction of the excess stays experienced, significant return on investment could be obtained. If dementia specialist nurses were able to reduce hospital stay for older people by one day on average, an annual return on investment of 37% could be achieved with a net saving of nearly £11,000,000 nationally.

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Appendix 1: Survey of UK dementia nurse specialists working in acute care

21,760 Royal College of Nursing members who had previously identified an interest in dementia, care for older people or mental health were approached. Dementia nurse specialists, those working primarily with people with dementia and those supporting people with dementia in a general hospital setting were invited to respond. 565 people responded and from these responses we identified 75 nurses whose job title indicated that they were specialist nurses working in an inpatient environment and who identified dementia care as the main function (23/75) or a substantial part (52/75) of their role. Of those who identified dementia care as their main role 16/23 identified dementia as their specialty, 6 mental health and 1 care for older people. The identified specialty for those who indicated dementia was a substantial part of the role varied but in almost all cases was a combination of older people and or mental health (Table 1)

Table 1	Is the care of people with dementia a part of your remit?		
Specialty (as indicated in job title)?	a substantial part of role	main function	Grand Total
Care for older people	20	1	21
Dementia care		16	16
Mental health	24	6	30
Older people's mental health	4		4
Other	4		4
Grand Total	52	23	75

Clinical areas supported

Most specialists supported / worked in a diverse range of clinical areas, suggesting a wide remit which often appeared to be trust wide, although a small number appeared to focus on wards for older people and or medicine exclusively and one accident and emergency / admissions. Older people, admissions, medical and orthopaedics were the areas most frequently covered (table 2). The pattern of coverage seemed broadly similar for specialists whose main role was dementia care as for others.

Table 2	Clinical areas you work in / support		
	a substantial part of role	main function	Grand Total
Older peoples ward	43	19	62
Admissions unit	31	19	50
Medical ward	33	16	49
Orthopaedics	32	16	48
Accident and emergency	23	12	25
Dementia Ward	13	9	22
Minor Injuries	8	8	16
Theatres	3	5	
Grand Total	52	23	75

Management arrangements

Management arrangements were diverse although none indicated that they were managed by a consultant physician and only one indicated management by the trust lead clinician for dementia. The commonest

arrangements for those whose main function was to provide dementia care was management by director of nursing (5) or directorate nurse manager (4). For others management from outside the hospital was common, presumably reflecting the mental health specialism.

Roles

Table 2	What do you spend MOST time on (multiple choices allowed for equal contributions)		
	a substantial part of role	main function	Grand Total
Direct patient care	30	11	41
Consultancy	25	14	39
Education	15	12	27
Leadership	13	11	24
Evaluation	5	7	12
Grand Total	52	23	75

Overall, the activity that specialists identified spending most time on was direct patient care (41/75) although for specialists whose main function was dementia care more identified consultancy (14/23) and education (12/23) rather than direct patient care (11/23) as the activity consuming most time. Leadership (11/23) was also identified by a large number of these nurses.

1. Clinical

Table 3	Role in dementia care		All
	a substantial part of role	main function	Grand Total
Participating in discharge planning for individual patients	40	20	60
Supporting families/significant others	43	22	54
Assessing and diagnosing dementia	37	15	52
Developing individualised care plans	33	16	49
Screening of patients for cognitive impairment	35	13	48
Providing therapeutic interventions for challenging / distressed behaviour	27	16	43
Sharing diagnosis	27	10	37
Providing direct help to patients to involve them in decision-making	32	14	36
Providing direct care to patients	22	11	33
Reviewing medications	30	13	33
Prescribing medications	11	2	13
Grand Total	52	23	75

Specialists described a diverse range of clinical roles with discharge planning and support to families identified by most. Assessment, diagnosis and screening were also frequently identified as was care planning. Providing therapeutic interventions for challenging / distressed behaviour was undertaken by significant numbers including most (16/23) of those whose main role was dementia care. While reviewing medications was undertaken by many (33/75), few prescribed (13/75) [table

2. Consultancy

Table 4 Consultancy topics	Role in dementia care		All
	a substantial part of role	main function	Grand Total
appropriate physical environments for people with dementia	42	20	64
confusion or delirium	45	19	64
challenging/ distressed behaviour	43	19	62
best interest decisions for individual patients	40	18	60
cognitive assessment and identification of people with possible dementia	41	18	59
safeguarding issues	41	17	58
hydration and nutrition for people with dementia	36	19	55
end of life care for people with dementia	32	17	49
Mental Capacity Act assessments	32	17	49
falls prevention for people with dementia	30	17	47
provision of appropriate activity / rehabilitation potential	30	17	47
advance planning for people with dementia	31	14	45
Grand Total	52	23	75

Consultancy was performed on a range of topics and while there was some diversity a substantial majority provided consultancy on appropriate physical environment (64/75), confusion / delirium (64/75) challenging or distressed behaviour (62/75) and best interest decisions (60/75). Other areas were also frequently identified including cognitive assessment, hydration and nutrition and fall prevention, although this was slightly less common (47/75)

3. Education

Table 5 Educational roles (staff)	Role in dementia care		All
	a substantial part of role	main function	Grand Total
Teaching sessions for nurses/doctors/other staff about dementia care	52	23	75
Informal education for nurses/doctors/other staff about dementia care	43	21	64
Role-modelling good practice in dementia care to staff	39	18	57
Supporting ward- or department-based “dementia champions” in their role	33	19	52
Contributing to the design and/ or delivery of undergraduate and postgraduate education	14	12	36
Leading practice development in relation to dementia care	20	14	34
Grand Total	52	23	75

All the specialist nurses (75/75) provided formal teaching for other staff about dementia care and most also provided informal education (64/75) and role modelling (57) as part of their educational role. A majority also supported local dementia ‘champions’ (52/75) although only a minority (34/75) identified leading practice development for dementia as part of their educational role (table 5).

4. Leadership

Table 6 Leadership roles	Role in dementia care		All
	a substantial part of role	main function	Grand Total
Developing hospital/ward practices, policies, pathways / protocols, guidelines and procedures to ensure wellbeing of patients with dementia and their carers	31	16	47
Establishing relationships with local authorities, primary and community care, voluntary and independent sectors	27	19	46
Reviewing and introducing assessment scales/patient communication aids/other resources into practice	20	16	36
Developing hospital/ward practices, policies, guidelines and procedures for supporting and working in partnership with carers	20	13	33
Leading trust-wide developments in dementia care	16	16	32
Providing trust-wide strategic leadership on dementia care	10	13	23
Grand Total	52	23	75

Most, but not all (47/75) identified the development of practice including protocols, guidelines and procedures for care of people with dementia as part of their role, with fewer (33/75) identifying practice and procedures for working in partnership with carers as part of their leadership role. Leading trust wide developments (32/75) and providing strategic leadership (23/75) was identified by only a minority (table 6).

Expected Impacts

We asked respondents if they had been asked to demonstrate the impact of their role on a number of outcomes (table 7). Responses here may be indicative of a number of issues (including variation in the extent of evaluation) but the range of outcomes identified does suggest the broad range of issues that specialist nurses may be expected to address and both the challenge and the opportunity for making a difference. No one outcome was identified by a majority of respondents but staff development (33/75) and discharge outcomes (32/75) were the most frequently identified with length of stay (31/33) patient carer satisfaction (26/75) and use of anti-psychotic medication (25/75) also relatively common.

Table7 Expected impacts	Role in dementia care		All
	a substantial part of role	main function	Grand Total
Staff development	18	15	33
Discharge outcomes	21	11	32
Length of stay	20	11	31
Patient/Carer satisfaction	15	11	26
Use of anti-psychotic medication	13	12	25
Readmission rates	16	8	24
Falls	14	6	20
Pressure area care	8	2	10
Violent incidents	5	5	10
Grand Total	52	23	75

Qualifications.

Table 8	Qualifications		
	a substantial part of role	main function	Grand Total
Professional			
RN (general)	30	11	41
RN (mental health)	33	16	49
RN (learning disabilities)	2	2	4
Academic			
Bachelors qualification	33	10	43
Master's degree	11	6	17
PhD	2	0	2
Grand Total	52	23	75

Many nurses had dual qualification (e.g. RN / RMN) with the largest group having a mental health qualification (49/75). 43/75 held a bachelor's degree but only 17/75 had a master's (which is seen as the minimum qualification for a specialist nurse in many jurisdictions).

Line management

Few of the specialists managed any staff (18/75) and for those who did, the team under them was typically six people or fewer (for 15/18). For those whose main function was dementia care, the teams that they managed were diverse in job titles and professional qualifications but appeared equally divided between professional and support staff. Line management for specialists was often outside the hospital (13/75) with large numbers being managed by a directorate nursing manager (13/75) director of nursing (10/75) or other senior nurse (e.g. matron). None reported being managed by a consultant physician/geriatrician/psychiatrist and only one by the trust lead for dementia.