Specialist nurses should form part of the post-diagnostic care and support network for living well with dementia

Dr Shibley Rahman
@AlzheimerEurope : 2015 Ljubljana
Thursday, 3 September 2015

14.00–15.30 (M1) Parallel Session P4: Timely diagnosis
This is the final session in this symposium stream

P4.1. National audit of memory clinics in England: a comparison of findings

P4.2. The use of ICT for the assessment of people with dementia and mild cognitive impairment within the Dem@care project

P4.3. You are happy and safe: a discourse analysis of a diagnostic disclosure of dementia

P4.4. Leveraging volunteers in retirement communities to increase diagnosis of dementia

P4.5. Specialist nurses should form part of the post-diagnostic care and support network for living well with dementia
THANK YOU!
P4.5. Specialist nurses should form part of the post-diagnostic care and support network for living well with dementia

Objectives: There have been numerous concerns that the health and care system in England is too fragmented, and lacks sufficient focus for a person with dementia or caregiver to navigate through the system. This makes it difficult for people to live well with dementia. The aim of this study was to conduct a preliminary online survey into citizens’ attitudes to what post-diagnostic support in the English jurisdiction could look like.

Methods: 90 respondents completed the online “SurveyMonkey” survey, invited from a Twitter account with around 13000 followers. The survey could only be completed once. Participants were invited to be a person who had just received a “timely” diagnosis of dementia in the English jurisdiction.

Results: You were most likely to see your General Practitioner if you were aware of dementia and had noticed memory problems (49%) rather than simply talk to friends and family (33%), but you were likely to take action as soon as possible (92%). You were most likely to wish to have follow up from a neurologist and community psychiatric nurse (39%), with input from a specialist nurse in a multidisciplinary team (74%). However, you would (just) prefer to have a specialist nurse as your ‘care coordinator’ (47%) rather than a “dementia adviser” (34%), but to have a primary caregiver’s input in formulating a personalised care plan (46%). (Respondents further stated that the decision to implement clinical nursing specialists should be based on clinical outcomes (76%).

Conclusion: The results from this preliminary survey identify the clinical nursing specialist as key stakeholder of future importance in the English jurisdiction, working together with a person living with dementia and the primary caregiver in the post-diagnostic care and support network. This will vastly improve likelihood of living well with dementia.
• Background
• Aim
• Methods
• Results
• Discussion
• Conclusion
Background

There have been numerous concerns that the health and care system in England is too fragmented,

and lacks sufficient focus for a person with dementia or caregiver to *navigate* through the system.
Access to intelligent technology
Access to justice
Community based resources, e.g.
  leisure and recreational facilities
Education and learning opportunities
Employment opportunities
Financial wellbeing
Housing
Social networks
The built environment, including
  shared open spaces
Transport

Figure 10.2 An ‘integrated approach’ to dementia post-diagnostic care and support
TIME FOR SOME ADVANCED THINKING?
THE BENEFITS OF SPECIALIST NURSES

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HSJ February 2015 – supplement on clinical nursing specialists

- Care at reduced cost and increased efficiency
- System leadership and service redesign
- Seamless, integrated, multidisciplinary care
- Treating the person, not the condition (delivering whole person-centred care)
- Excellent patient care and experience – note, NHS Outcomes Framework, also avoidance of hospital admissions
- Bringing care closer to home and reducing the burden of long term conditions (note, self management and self care)
Clinical nurse specialists: adding value to care

An executive summary
Making a Difference in Dementia: Nursing Vision and Strategy

Model for Dementia Nursing
Dementia Specialists – Experts in the field of Dementia care
- Nurses with an expert level of skill and knowledge / specialist role / 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 delivering changes in practice.

Dementia Skilled – All providing nursing to people with dementia directly
- All nurses that have more regular and intense contact with people with dementia, providing specific interventions, care and services.
- They have an enhanced knowledge and are skilled in dementia care.

Dementia Awareness – All Nurses
All nurses to have an awareness of dementia:
- Basic training;
- Making every contact count;
- Able to support and signpost public health messages.

Intensive or Case Management
- e.g. Admiral Nurse, dementia specialist nurse

Assisted Care or Care Management
- e.g. mental health nurse, liaison nurse, community matron, care home nurse, hospital nurse

Usual Care with Support
- e.g. district nurse, practice nurse, PHN

Developing and delivering seamless services within the person’s home, community, hospital settings and between the two
Caroline Lucas (Brighton, Pavilion) (Green): It has been estimated that entrenching market structures in the NHS, for example through tendering, bidding and contracting to the private sector, costs over £10 billion a year. Why does the Prime Minister not think that that money would be better spent on patient care?

The Prime Minister: What we have done is save money by cutting out bureaucracy, so we are seeing an extra £4.5 billion go into the NHS. If the hon. Lady is saying that there is no occasion at all when anyone from the independent, charitable or voluntary sectors can help in our NHS, I think that she is wrong. I think of the work that Macmillan cancer nurses and Marie Curie Cancer Care do, helping with the end of life. The idea that there is only one way to deliver health care in our brilliant NHS, which is expanding under this Government, is completely wrong.
Aim

A preliminary online survey into citizens’ attitudes to what post-diagnostic support after a timely diagnosis in the English jurisdiction could look like.
The higglepiggledy nature of ‘post diagnostic support’, with huge gaps, makes it difficult for people to live better with dementia.
Methods

• 90 respondents completed the online “SurveyMonkey” survey, invited from a Twitter account with around 13000 followers.

• The survey could only be completed once.

• Participants were invited to be a person who had just received a “timely” diagnosis of dementia in the English jurisdiction.

SEVEN QUESTIONS
Results
Seeking a diagnosis (Q1)

The year is 2015.

Say you’re an adult aged between 45 – 55 with no previous significant medical or surgical history.

You’ve noticed a sharp decline in your memory in the last few months.

You’ve heard a lot about dementia in the recent Government awareness campaign, and have recently attended a 'Dementia Friends’ session in your local church.

What would you do next?
A. Do nothing for the timebeing, and avoid the possibility of receiving a diagnosis of early dementia. (18%)

B. Go to see your General Practitioner with a view to receiving, if correct, a diagnosis of early dementia. (51%)

C. Talk about your concerns with your friends or family, to see what they suggest. (31%)
Choosing follow up (Q2)

The year is 2015.

You have had a meeting with a General Practitioner ("GP"), who organised for some appropriate investigations to be completed.

The GP has now informed you that the most likely diagnosis is early Alzheimer’s disease, a condition where memory and attention will be your biggest problems in the near future.

You are told by the GP that there are certain medications which might help with symptoms for about six months, but there are no known cures which slow disease progression.

You took along to this meeting a close family friend.

What would be your preference now?
<table>
<thead>
<tr>
<th>Answer Choices</th>
<th>Responses</th>
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<tbody>
<tr>
<td>Stay with your GP, but attend for the next couple of years regular six-monthly meetings with a hospital neurologist to observe follow-up. A Community Psychiatric nurse will come to see you when required.</td>
<td>40.66% 37</td>
</tr>
<tr>
<td>Stay with your GP, but ring up a local charity helpline to see what they can suggest to help you, regarding information and life choices.</td>
<td>25.27% 23</td>
</tr>
<tr>
<td>Stay with your GP, who can help organise care and support for you and your closest consisting of a multidisciplinary team.</td>
<td>34.07% 31</td>
</tr>
<tr>
<td>Total</td>
<td>91</td>
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</table>
The year is 2015.

You are now the partner of somebody who has just, aged 59, received a likely diagnosis of dementia. You are told that in the early stages this dementia is best characterised by language and planning problems.

You and your partner choose to stay with your GP, who can help organise care and support for you and your closest with a multidisciplinary team.

You always give full consent for you and your partner to make decisions together. Your physical health is otherwise very good.

The GP, a community psychiatric nurse, a community occupational therapist, and consultant neurologist already form part of your care package.

**Who would you most like in your multidisciplinary team, in addition?**
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<tr>
<th>Answer Choices</th>
<th>Responses</th>
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<tbody>
<tr>
<td>a clinical nursing specialist, a clinical psychologist, a speech and language therapist.</td>
<td>73.33%</td>
</tr>
<tr>
<td>a clinical psychologist, a speech and language therapist.</td>
<td>12.22%</td>
</tr>
<tr>
<td>a clinical psychologist only.</td>
<td>14.44%</td>
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<tr>
<td><strong>Total</strong></td>
<td><strong>90</strong></td>
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</tbody>
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How long to wait till follow up? (Q4)

The year is 2015, and your GP and her colleagues have made a reliable diagnosis of dementia which had been initiated by symptoms of worsening memory.

You are 56, and were not due to retire until 2021.

You do happen to know that you will get a full pension package on retirement which you could take at any time due to ill health.

You live on your own, in a bungalow, with no close friends or family.

For some time, you don't hear anything about any follow up.

How long would you wait until you decide to initiate follow up of your own?
Answered: 89  Skipped: 4

- 2017
- 2019
- beyond 2021

0% 10% 20% 30% 40% 50% 60% 70% 80% 90% 100%
Who should be the care coordinator? (Q5)

The year is 2016.

You are aged 56, and you have been diagnosed with early onset dementia.

Integrated health and care packages are organised through your local NHS.

You and your partner would like an appointed individual to ‘be there’ during the course of this journey as a "care coordinator", in addition to a named social care practitioner.

Who would you like to be this care coordinator?
A. GP. (20%)

B. Clinical nursing specialist. (47%)

C. ‘Dementia advisor’ from a well known dementia charity. (33%)
Making the care plan (Q6)

The year is 2016.

You are aged 56, and you have been diagnosed with early onset dementia characterised by progressive language difficulties.

You have no significant medical or surgical history. Integrated health and care packages are organised through your local NHS.

You have been advised to have a care plan ready which might be referred to, should you need to go to hospital.

Who would you most like to help you organise a care plan?
<table>
<thead>
<tr>
<th>Answer Choices</th>
<th>Responses</th>
</tr>
</thead>
<tbody>
<tr>
<td>A speech and language specialist, who might anticipate communication problems on your possible hospital admission.</td>
<td>20.00% 18</td>
</tr>
<tr>
<td>Your partner who acts as your main caregiver.</td>
<td>45.56% 41</td>
</tr>
<tr>
<td>A clinical nursing specialist.</td>
<td>34.44% 31</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>90</strong></td>
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</table>
How to influence policy (Q7)

Currently, nationally, a clinical nursing specialist is considered one of the options ‘on the table’ to improve the English dementia policy.

On what basis do you think a decision to roll-out a national programme of clinical nursing specialists in dementia should be decided?
<table>
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<tr>
<th>Answer Choices</th>
<th>Responses</th>
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<tbody>
<tr>
<td>powerful lobbying from charities (&quot;third sector&quot;)</td>
<td>10.00%</td>
</tr>
<tr>
<td>financial considerations of NHS and care funding</td>
<td>13.33%</td>
</tr>
<tr>
<td>clinical outcomes</td>
<td>76.67%</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>90</strong></td>
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Discussion
Our vision, in line with the Glasgow Declaration (2014) is that overall people in Scotland will have the right to:

- A timely diagnosis.
- Access quality post-diagnostic support.
- Person centred, co-ordinated, quality care throughout their illness.
- Equitable access to treatments and therapeutic interventions.
- Be respected as an individual in their community.

Focus on Dementia aims to build resilience for people with dementia and their families, avoiding crises including unnecessary admission to hospital and institutional care settings. Where hospital admission is unavoidable, the care experience is safe, co-ordinated, dignified and person centred, ensuring seamless transition across care settings. In order to achieve this aim, the programme is undertaking the following activity:
Box 10.3 Potential different roles of the ‘care coordinator’

* Essentially non-medical entities

* Might involve very close friends, family, state agencies, occupational therapist, dietitian, physiotherapist, social care worker, faith groups, transport, translators, suppliers of assistive technology

* Manage care plan (including monitoring of progress of key contracts with key providers)

* Manage out-of-hospital support

* Manage discharge from hospitals

* Integration of information from different care settings

* Volunteering in other roles when required
The role of a clinical nurse consultant dementia specialist: A qualitative evaluation

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Royal District Nursing Service, Altona, Victoria, Australia

Dianne P Goeman, Chris J Beanland and Susan H Koch
Royal District Nursing Service, RDNS Institute, St Kilda, Victoria, Australia

There is a growing body of evidence that ‘timely’ diagnosis promotes psychological wellbeing for the person with dementia as well as the carer (Aggarwal, Vass, Minardi, Ward, Farfield, & Cybyk, 2003; Koch, Marks, & Hofmeyer, 2002; Prince, Bryce, & Ferri, 2011; Wackerbarth & Johnson, 2002). ‘Timely’ being a response to patient and carer concerns rather than proactively screening for dementia (Philips, Pond, & Goode, 2011). We therefore developed and refined the role of a clinical nurse consultant (CNC) with a speciality in dementia to provide person-centred pre-diagnosis support to address the growing need for assistance by those experiencing cognitive changes, as well as their families and carers.
Innovative use of electronic health record reports by clinical nurse specialists.

Purvis S¹, Brenny-Fitzpatrick M.

Abstract

PURPOSE: The purpose of the study was to demonstrate how clinical nurse specialists (CNSs) can use information pulled from the electronic health record (EHR) in innovative ways to improve nursing care of vulnerable older adults.

BACKGROUND: As the number of older adults increases, the need will grow for easier access to evidence-based practice nursing interventions for the older population. Clinical nurse specialists are the experts in evaluating research and will also need to find innovative ways to bring the evidence-based practice pertinent to the care of older adults to the bedside nurse.

DESCRIPTION OF THE PROJECT/INNOVATION: Clinical information from various parts of the EHR is pulled into computer-generated reports that focus on identifying older adult patients with specific high-risk indicators. The specific clinical information pulled into the reports and examples of how the reports are used will be presented. Four reports are described including new hospital admissions of patients older than 65 years, current hospitalized patients with dementia/delirium, current hospitalized patients on cholinesterase inhibitors, and a comprehensive report of all current hospitalized patients older than 65 years focusing on specific geriatric indicators identified in the literature.

OUTCOMES/IMPLICATIONS: Computerized reports can be used to facilitate the use of nursing practice guidelines and evidence-based clinical tools such as the confusion assessment method and to increase use of nursing plans of care. The reports can also provide real-time key indicators that can be used to facilitate identification of older adult patients in need of CNS and/or geriatric team consultation. More research still needs to be done regarding the impact of the EHR on nursing indicators such as number of falls, delirium, and use of restraints.

PMID: 20940566 [PubMed - indexed for MEDLINE]
Figure 7.1 The Triangle of Care
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

Peter Griffiths, Jackie Bridges & Helen Sheldon
with
Ruth Bartlett & Katherine Hunt
“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.”
Conclusions

The results from this preliminary survey identify the clinical nursing specialist as key stakeholder of future importance in the English jurisdiction, working together with a person living with dementia and the primary caregiver in the post-diagnostic care and support network.

This will vastly improve likelihood of living well with dementia and improve the effectiveness of the health and social care services in England.
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