Dignity in dementia; transforming general hospital care

Summary of findings from survey of professionals; March 2011
(Analysis carried out by Employment Research Ltd)
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During January and February 2011 the Royal College of Nursing (RCN) invited responses from professionals about the delivery of care for people with dementia within general hospital settings. The survey was disseminated via RCN networks and a range of external organisations to help gather a range of perspectives on ways of improving care. Respondents were asked to provide details of initiatives and approaches that had helped to promote dignity, improve understanding and enhance the delivery of care. Information was gathered on the impact of developments as well as identifying factors that supported and hindered improvements.

A total of 712 responses were received from a range of professionals of which the majority were ward sisters/managers and/or other senior nurses such as matrons, clinical nurse specialists and consultant nurses. Responses from unqualified staff including healthcare assistants and assistant nurse practitioners totalled 4% (n=28). One in five respondents were from non-nursing backgrounds; including lecturers, doctors, occupational therapists, physiotherapists, discharge coordinators and a small number of students.

Figure 1: Respondent role (percentages) Source: Employment Research/RCN Dignity in Dementia Survey, 2011

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1 Note that the percentages do not sum to 100% as some respondents indicated more than one role
Respondents came from a variety of settings with 23% from older people’s wards and 27% from medical/surgical or general wards. Other settings included A & E, critical care e.g. intensive/ coronary care units, medical assessment units, and a small number from outpatients, stroke units, theatres, orthopaedics and palliative care. Approximately 6% of respondents (n= 42) identified working in a dementia specific setting.

Figure 2: Field of practice/specialty (percentages)

Source: Employment Research/RCN Dignity in Dementia Survey, 2011

Responses were distributed across the UK with the largest group of respondents located in the South East of England (16%), North West (13%), South West (12%) and London (10%). In terms of the other UK countries 9% of responses were from professionals working Scotland, 4% Wales and 2% Northern Ireland.
Nature of improvements to care

Findings from the survey indicate that a number of approaches (average of 5-6) are required to support improvements in care. Most important was the involvement of family carers (identified by 71% of respondents) and supporting the training and development of staff (69% of respondents). See Figure 3 overleaf.

Other significant approaches included: (in order of frequency)

- Developing person – centred care planning and strategies to respond to distress as informed by life history information e.g. ‘This is Me’.
- Improving identification, assessment and screening; supported by delirium protocols, dementia specialist or mental health liaison staff and initiatives such as the ‘Butterfly Scheme’.
- Improving meal times by identifying those who need assistance e.g. Red tray system, involving families/carers and volunteers in meal times, improving nutrition screening and making meal times more sociable.
- Improving end of life care by developing closer links with palliative care teams and specialists, supporting identification and management of pain e.g. Abbey Pain tool and recognition of end of life care needs e.g. implementation of Liverpool Care pathway.
- Improving the physical environment to make it more ‘dementia friendly’ e.g. use of clearer signs/images, large clocks, colours which help to identify contrasts, developing spaces/designated area to support activities etc.
- Changing visiting times to allow for more open access and involvement of families/supporters in care.
- Other examples included adapting routines such as washing/bathing to allow for flexibility and support individual needs, introducing more activity/therapies onto the ward such as music, games etc, and using volunteers to provide additional support.

‘This is Me’ is a document developed by the Alzheimer’s Society /RCN which can be completed and used to support care for people with dementia whilst in hospital. It includes information about the person as an individual, such as needs, preferences, likes, dislikes and interests. See http://www.alzheimers.org.uk/site/scripts/download_info.php?downloadID=399

The ‘Butterfly Scheme’, developed by a family carer, uses a discreet Butterfly symbol to support identification and provide principles to support staff with caring for people with dementia whilst in hospital.
Figure 3: Development of approaches to support dementia care (percentages)

- Involvement of family carers: 71%
- Education/training of staff: 69%
- Care planning: 57%
- Assessment/screening: 51%
- Meal times, for example: use of red trays, different menus etc.: 48%
- End of life care: 43%
- Physical environment e.g. signage, use of colours on doors etc.: 40%
- Visiting times: 35%
- Routine, for example: making routines such as washing, eating, at different times to fit to patient needs: 33%
- Activities, for example: reminiscence, cognitive stimulation therapy, music therapy, etc.: 30%
- Area/place in which people with dementia are cared for e.g. separate bays/beds etc: 26%
- Involvement of volunteers: 25%
- Other factors: 17%

Source: Employment Research/RCN Dignity in Dementia Survey, 2011

Delivering improvements

Additional information was gathered from respondents about how they had achieved and delivered approaches aimed at improving care for people with dementia in their settings.

Respondents emphasised the importance of having support from the Trust board to improve dementia care, support from senior nurses, mental health liaison & dedicated dementia posts to provide leadership, sharing knowledge between teams to share best practice and improving communication between support services & community care.
Specific factors considered to have **supported improvements** included: (see Figure 4)

- Implementation of a specific dementia pathway (mentioned by 40% of respondents)
- Funding to release staff for training (36%); some of which came from CQUIN and QIPP targets
- Support from external organisations (34%) including Kings Fund, Alzheimer’s Society,
- Links with other improvement initiatives (30%) particularly reducing falls & pressure sores and delirium guidelines.
- Other improvements referred to (37%) focused mainly on education and training strategies, support from senior nursing staff and involving families in care.

**Figure 4: Support provided for development of dementia care (percentages)**

![Bar chart showing percentages of support provided for development of dementia care](source)

*Source: Employment Research/RCN Dignity in Dementia Survey, 2011*
Education and training featured highly within feedback and a number of factors were considered to be particularly important including:

- Ensuring that all staff including domestic, porters, managers etc had access to training to improve awareness of dementia.
- Focusing on development of appropriate skills/attributes
- Involving family carers and/or people with dementia in the delivery of training
- Identifying leaders and other specialists such as mental health liaisons or dementia specialists who would be able to support staff
- Providing more in-depth training for ward champions and leaders.

On being asked about barriers to delivering improvements in care the most significant factors were considered to be pressure of existing workload and insufficient staffing levels which were mentioned by three quarters of all respondents. Approximately a half of respondents identified the movement of patients between wards/units (49%) as a barrier to providing good care and four in ten referred to an inappropriate environment in terms of lighting and space etc (43%). A lack of funds to support and drive improvements was identified as a barrier by 42% of respondents.

**Figure 5: Barriers to improving dementia care (percentages)**

![Graph showing the percentage indicating various barriers to improving dementia care. The graph categorizes factors such as pressure of existing workload, insufficient staffing levels, patients being moved, inappropriate environment, lack of funds, limited access to specialist support, lack of equipment, difficulty accessing education/training, and poor recognition and assessment.](image)

*Source: Employment Research/RCN Dignity in Dementia Survey, 2011*
Impact and outcomes of improvements

Respondents were asked to indicate what differences had been achieved as result of improvements to the delivery of care. Nearly three quarters of respondents said that there had been an improved understanding of the needs of people with dementia (72%) and around six in ten identified improved understanding of the needs of families/friends (61%).

Other identified outcomes included improvement in assessment and care planning (61%), improved recognition and identification of dementia (60%), improvements in supporting nutritional needs (58%) and increased staff confidence in treating people with dementia (57%).

In a third of cases (31%) respondents identified a reduction in use of antipsychotic medication and in 39% of cases, a reduction in the use of sedatives.

Figure 6: Difference made as a result of changes to dementia care (percentages)

Source: Employment Research/RCN Dignity in Dementia Survey, 2011
Evaluations

One in five respondents said they had evaluated the impact of the changes made to dementia care where they work which mostly included either audits of specific roles or were in connection with the national audit of dementia care.

Some evaluations included surveys of patients and families and had found there to be less anxiety and more trust built up through better understanding of needs.

In a number of cases, evaluations are currently in progress. However some early findings indicate reductions in distress, fewer patient incidents e.g. falls etc. and reduction in length of stay.

Next Steps

Findings from this survey will inform recommendations, guidance and resources to support the delivery of care for people with dementia and their families in general hospital settings. We are also gathering feedback from people with dementia and family carers to determine priorities for care and will be working with a range of external stakeholders to develop and disseminate this work.

For further information please see:

www.rcn.org.uk/dementia