Collaborative project to co-ordinate care for patients with dementia

An initiative that drew on local knowledge, resources and carer input has improved patients' experiences in Suffolk and, although specific to dementia services, the process could be applied to other settings, says the Suffolk Nurse Leaders Group

Summary

Health leaders from across Suffolk joined together in a collaborative action-learning project to identify ways of offering more productive and personalised care for patients with dementia and their carers. The project revealed a range of factors necessary for success, notably professional collaboration and effective facilitation. The outcome was a range of evidenced-based recommendations to improve care and efficiency, as well as ensuring that the quality, innovation, productivity and prevention (QIPP) agenda was met. The lessons can be applied not just in dementia care, but to other long-term and complex care situations.

Keywords

Action learning, carers, dementia, personalised care

THE ALZHEIMER'S Research Trust (2010) estimates that Alzheimer's disease costs the UK economy £23 billion a year, almost twice as much as cancer and three times as much as heart disease. Yet an Alzheimer's Society report (2009a) claims that standards of hospital care for people with dementia are unacceptable and that hospital stays often exacerbate patients' conditions.

There is, therefore, an urgent need for change in the provision of acute adult care to provide better outcomes for people with dementia. In response, all the chief nurses and directors of nursing in Suffolk, the most senior academics at University Campus Suffolk and other regional NHS representatives, led by Dorothy Kennerley, managed and delivered an action-learning project to generate more personalised and productive care for people with dementia in acute adult care.

NHS organisations in Suffolk and Great Yarmouth in Norfolk have already begun implementing the evidence-based recommendations that emerged from the project and plan even greater productivity gains in the near future. Key to the success of the project has been the inclusion of carers and those cared for, commissioners, academics and service providers, as well as a project facilitator. The project focused on dementia care, but the lessons learnt can be applied more generally to the care of people with long-term conditions and complex healthcare needs.

Background

The project found that much of the present system and process of acute care is not designed to meet the needs of people with dementia. People are expected, wherever possible, to adapt to hospital routines instead of vice versa, and this is particularly problematic for people with dementia who sometimes forget where they are and cannot make sense of their environment.

In addition, the largely contrast-free design of hospitals can challenge people with dementia who often have significant visual and visuoperceptual difficulties (Alzheimer's Society 2010). Meanwhile, operational management issues, such as emergency admissions, infection control and providing same-sex accommodation, can worsen the situation if people with dementia are moved around the hospital.

The Alzheimer's Society (2009a) reviewed the quality of care provided for people with dementia in hospitals nationally and found that those over the age of 65 occupy up to 25 per cent of hospital beds, that they often spend longer in hospital than other patients admitted for the same procedures, and that staff are unequipped to provide the care they need. It also found that 'hospitals are failing to provide acceptable standards of care for people with dementia'.

The Suffolk Nurse Leaders Group (SNLG) therefore arranged for three project leaders from West Suffolk Hospital NHS Trust, James Paget University Hospitals

NHS Foundation Trust and Great Yarmouth and Waveney Primary Care Trust to work together to advise how to improve the productivity of care for people with dementia across the whole health economy.

The project

The group identified several simple and cost-effective changes to the delivery of care that, when applied across local health organisations, could dramatically improve patients' and carers' experiences while increasing productivity and meeting the QIPP agenda ethically. These could then be shared locally, regionally and nationally.

The group also aimed to support individual leaders in implementing changes to service delivery, recommending where and how these new ideas could be applied to the wider health economy.

Nicole Day, chief nurse at West Suffolk Hospital NHS Trust, was accountable for the project on behalf of the Suffolk County Workforce Group. The overall responsibility for delivering the project and supervising the project leaders was given to Dorothy Kennerley, a consultant and former senior health academic.

The project had three phases, which each concluded with a one-day meeting of project leaders and the SNLG to monitor progress, discuss key issues and agree next steps.

The first phase was information gathering and literature searching by the project leaders and facilitator. The second phase was analysing evidence and current practice and selecting areas for improvement. The final phase was creating business and implementation plans and gaining organisation support for proposed changes. The second and third phases were undertaken by project leaders with input from the project facilitator and directors of nursing, who sponsored their involvement.

Involvement

The project required quick and effective results. Selecting individuals who were clinically credible, could offer a balance of skills and could be released from their day roles to take part in the project was therefore vital. This latter part was challenging, so the project was designed to ensure that individuals could be involved at various stages through virtual communication, so that few face-to-face meetings were held. Meetings were designed for people to brief each other and the SNLG and to agree next steps.

It is vital to have an overall facilitator in such a project to provide focus, oversight and integration. Ms Kennerley was selected for this project because she has expertise in leading complex projects and finding and using available evidence. As a consultant, she was also able to devote the necessary time to the project.

Importantly, clear boundaries and expectations for all involved were negotiated at the outset. Individual directors of nursing and chief nurses were accountable for their staff acting as project leaders, and supporting them to deliver outcomes in their organisations in line with trust operational plans. The facilitator offered regular support and reviews of progress and addressed any difficulties that arose. She ensured that decisions were evidence based, supported and encouraged the creativity of project members, and offered focus, direction and understanding of the culture of different organisations.

The two matrons, Julie Fountain and Barry Pinkney, were selected as project leaders because they know about existing local provision of dementia care and had demonstrated an ability to introduce innovation to the care of this patient group. They were also well respected in their trusts and local health economies.

Allied health professional Kirsty Dawson, a clinical specialist podiatrist, was chosen as the third project leader. Neither she nor Ms Kennerley had a history of service provision, which added vital objectivity. They could challenge traditional thinking and request evidence to support assumptions about service delivery, such as the idea that hospital admission would provide respite for carers, who would not want to be involved in care during the period of admission. Carers pointed out that this is not always true.

Although this process of questioning assumptions was not always comfortable, it proved effective in providing more personalised productive care.

Investigation phase The group members pooled knowledge and experience of the evidence base, the clinical and operational opportunities and constraints, and the management of change of clinical care. The project leaders investigated local and international dementia care initiatives and reviewed the evidence base for the care of people with dementia in acute adult care settings. They shared the results of the joint comparative literature search using email. The project leaders also talked to carers and staff about what impeded the provision of the best possible care and visited centres of excellence.

They then presented their findings and ideas for improvement, many of which were cross-organisational, to members of the SNLG, who

acted as consultants and contributed their expertise to refine proposals. Senior academic members of the SNLG in particular played a valuable role in testing the evidence base.

Decision-making process Although the project leaders identified many potential innovations to improve acute dementia care, they were required to focus on a few aspects that were based on criteria they had generated. These included:

- Innovations most likely to improve productivity.
- Innovations that were acceptable in terms of commissioning and operational plans.
- Innovations achievable given that the project had time-limited funding.

The SNLG members were responsible for heading any innovations identified by the project team in their organisations to make them mainstream. They had a week to test the ideas before deciding which to prioritise. For most, this included debating the ideas in the wider trust or with commissioning groups.

This was a vital stage of the change management process: it stopped ideas that might be well intentioned but not part of trusts' overall strategies or those that were already in progress elsewhere from being implemented.

The SNLG and the NHS Suffolk County Workforce Group, which sponsored the project, then voted online to prioritise three areas for further development. These were:

- To make the hospital environment more suitable for people with complex needs, including dementia.
- To introduce the patient information booklet, This Is Me (Alzheimer's Society 2009b), across the health economy.
- To plan how to introduce a key worker at band 3 or 4 to support the primary care of people with complex needs, including those with dementia.

Project outcomes

Seven evidenced-based proposals were generated from the three priorities and have now been implemented (Box 1). Other longer-term improvements are planned.

The benefits of these initiatives have been immediate. For example, greater involvement of primary carers in acute care avoids potentially stressful events for people with dementia and reduces the risk of complications, such as poor nutrition, during recovery. This, in turn, reduces the time spent in hospital and allows patients and their carers to return more quickly to familiar and less stressful environments, reducing cost and resource pressures on hospitals.

Box 1 Seven ways to improve dementia care in acute adult care

- Consistent use of the This Is Me system of patients' help notes. Pioneered by the RCN and Alzheimer's Society in 2009, the system provides better individualised care and contributes to a more meaningful care experience.
- The assessment and planning of the needs of carers and people being cared for together in primary and secondary care.
- Including patients and primary carers in all consultations by NHS staff in clinics, during primary care visits, and throughout acute adult and mental health care.
- Promoting an open approach to care by copying all discharge, clinic and referral letters to patients.
- Creating and piloting systems that provide safe and improved access of principal carers to acute services, allowing them greater access during ward rounds, case conferences and mealtimes.
- Resolving issues related to emergency pressures created by ward closures, the resultant exclusion of carers and the impact of this on people with dementia.
- Promoting staff knowledge and understanding of dementia.

Involving carers as much as possible in acute care can also help reduce their stress, which improves the lives of their relatives with Alzheimer's disease. One trust has started a Caring for Carers project group to improve carers' experiences and has set up a 'key carer' system, which allows designated carers to come to the hospital outside visiting times and be involved in patients' care as they wish.

An implementation plan has been developed to embed the use of This Is Me (Alzheimer's Society 2009b) across the Suffolk health economy. These booklets are carried by people with dementia: they provide information about them, covering everything from nutritional and wellbeing information to their hobbies and interests.

Efforts are being made to ensure that the booklets accompany patients and are not lost or filed. The local ambulance trust has a role in this and has agreed to support the process by identifying patients who have the booklets and ensuring that they accompany them during transfer.

This Is Me is now used for people with dementia in units in all acute care trusts in the county, and the effects are being monitored in each trust. The local Alzheimer's Society has already noted greater

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uptake of services. One trust has added a 'more about me' section to the leaflet to provide additional information about patients' nutritional and hydration requirements; another has introduced picture menus to promote better nutrition; and a third is undertaking a carers' survey that includes a question on This Is Me to audit implementation.

Trusts across Suffolk are also implementing some minor, cost-effective measures on those hospital wards that have a high prevalence of people with dementia, using the evidence-based design ideas from the Dementia Services Development Centre at Stirling University (2009).

These changes include creating more colour contrast using the red/yellow spectrum: for example using red-coloured toilet seats on white toilets, red bedding on white bottom sheets, and red jugs and dining trays to increase the visual contrast and improve the visuoperceptual environment for people with dementia.

Another simple step is to make energy-saving measures for lighting a lower priority in ward areas with a high prevalence of patients with dementia. This avoids having areas of low or no lighting, which helps to minimise potential problems that patients may have during hospital admissions in terms of their orientation and experience.

All trusts in the county are making progress with major changes to the physical environment. One proposal to improve care for people with dementia, Enhancing the Healing Environment (King's Fund 2000), has been agreed to start this month. The group is also planning to create dedicated day rooms in all local acute hospitals for patients with dementia and their carers: a prolonged stay in ward areas can harm their wellbeing and that of other patients. According to Cantley and Wilson (2002), 'people with dementia particularly benefit from an environment that provides… familiar features and homely style… additional space for daytime activities'. Meanwhile, Alessi *et al* (1999) report that daytime exercise helps reduce daytime agitation and nighttime restlessness for people with dementia.

While the ethos of care in acute hospitals is to minimise patient stays, there are often delays in the discharge process. Providing a dedicated room with an enclosed garden could go some way to meeting patients' needs and supporting their wellbeing.

Following a review of facilities in one trust, dayroom refurbishment across all inpatient areas started in April.

Directors of nursing and executive chief nurses are leading the way on improving dementia care, a non-executive director is championing the needs of this client group in each acute trust, and a range of training initiatives is supporting the changes. These include:

- Developing dementia champions in clinical areas.
- Including dementia awareness in mandatory training.
- Ensuring that the mental-health complex-care teams work in the acute trust to support patients, carers and staff.
- Having an Alzheimer's Society trainer assist with action-learning and scenario-based approaches to encourage teams to develop better care together.

Longer term proposals include implementation of a new service to create a community-based key worker role to support people with dementia and their carers. The service is designed to run between 3pm and 8pm every day, including bank holidays, and aims to provide support to carers of people with dementia during the most difficult parts of their days to try to avoid unnecessary admissions to hospital.

Lessons learnt

The project identified productivity gains, particularly where staff and carer resources could be employed more usefully to avoid patient discomfort and disturbance. By comparing radically different ways of providing services to people with dementia, the SNLG produced new service specifications and commissioning criteria based on its analysis of best care for patients, making care more personalised and service delivery more productive.

The project also improved communication between the Suffolk and Waveney organisations involved in the provision of care and provided elements of co-supervision and co-consultancy. This enabled the achievement of the project outcomes and allowed smooth implementation of the proposed changes.

The mix of expertise, academic input and an objective, evidenced-based approach to developing solutions was central to the project's success. The project also revealed the benefits of collaboration: strong outcomes, mutual professional development opportunities, and the power of a collective voice. Ensuring carers were involved in the project gave valuable insights into their and their loved ones' needs and a shared commitment to improving care.

It also revealed clear messages from lay carers who want a joined-up service to support their needs

as they arise, and respect and dignity for those they care for. Many said they also want a greater level of involvement in acute care, where there is a tendency to assume that carers want a 'rest' while their loved ones are in hospital. For some people this is the case, but carers can make a critical contribution to the quality of care delivered if their expertise is embraced and they are involved in the way they want to be: the carer is usually the expert about an individual's care and this highly skilled support is often wasted.

Crucially, the 'bigger picture' has remained in view throughout this project: group discussions included relevant strategic issues such as the effect of regulation, leadership styles, organisational culture and values, protection of vulnerable adults, human rights, and estates issues.

Challenges Some of the challenges faced during the implementation phase of the project included:

- Projects becoming 'lost' when senior staff move.
- Carers feeling disappointed by lack of progress.
- Workload pressures and the pace of change preventing the SNLG functioning as a group to provide support for change.
- Directors of nursing focusing too much on immediate day-to-day priorities, missing the bigger picture and failing to appreciate the need to lead the necessary changes.
- The potential of the government's white paper (Department of Health 2010) to limit nurse clinical leadership.

Implementation of this project required making directors of nursing accountable for maximising the delivery of the project's outcomes as commissioners and providers. There also has to be visible commitment from nurse leaders and trust boards, educational input from local higher education institutions across pre- and post-registration programmes, and a facilitator to assist the project.

In addition, the involvement of mental health trusts to provide advice and guidance at grass-roots and strategic levels was important in ensuring joined-up services, something carers indicated as critical.

Finally, there must be recognition that the speed of implementation will vary across the county, and expectations of staff, carers and patients need to be managed accordingly.

Conclusion

The SNLG has implemented some simple but immediate changes across the local health economy, and is planning longer term initiatives to enhance service provision, which include:

- Cost-effective, targeted training and development.
- Providing more integrated systems of case management to provide greater continuity of support to service users and their carers.
- Using assistive technology to support care closer to home.

These will take time to implement, but will result in the delivery of a more productive service that demonstrates compassion, engagement and respect for people with dementia and their carers.

All the changes are clinically led, implemented and evaluated and, importantly, the project has shown that, even in a time of economic constraint, healthcare provision can be enhanced and productivity improved. Focused leaders working together can make a big difference and meeting the QIPP agenda is achievable without compromising professional standards.

This is a significant piece of work, but it is only the beginning. The number of patients with dementia and other complex needs who present to acute hospitals will continue to increase, so hospitals must prepare to improve significantly the standards of care for these patients.

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