Optimising acute care for people with dementia: a mixed-methods study.

Rahil Sanatinia[1], Mike J Crawford[1,2]*, Alan Quirk[2], Chloe Hood[2], Fabiana Gordon[3] Peter Crome[4], Sophie Staniszewska[5], Gemma Zafarani[1], Sara Hammond[1], Alistair Burns[6], Kate Seers[5].

1 Centre for Psychiatry, Imperial College, London, UK.

2 College Centre for Quality Improvement, Royal College of Psychiatrists, London, UK.

3 Population Health Sciences, University of Bristol, Bristol, UK.

4 Research Department of Primary Care and Population Health, University College London, London, UK.

5 Warwick Research in Nursing, Warwick Medical School, University of Warwick, Warwick, UK.

6 Faculty of Medical and Human Sciences, University of Manchester, Manchester, UK.

Corresponding author: **Dr Rahil Sanatinia, r.sanatinia@imperial.ac.uk**

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for the National Audit of Dementia and has been on the HTA PCCPI Panel and HTA Prioritisation Committee A (Out of Hospital). Professor Kate Seers has been a member of the HS&DR Commissioning Board (Researcher Led). Professor Sophie Staniszewska has been on the following committees: HS&DR Associate Board Members; HS&DR Researcher Led - Associate Board Members; INVOLVE BOARD. All authors declare no other competing interests.

Scientific Summary

Background

The number of people with dementia who are admitted to acute hospitals is increasing. The unfamiliar environment and disruption to daily routines that people with dementia experience when they are admitted to hospital can cause emotional distress and exacerbate their condition. Compared to other inpatients, people with dementia spend more time in hospital and are more likely to be readmitted following their discharge.

Concerns have repeatedly been expressed about the quality of care that people with dementia receive when admitted to acute hospitals. National audits examining acute care for people with dementia have shown that many do not receive a comprehensive assessment of their needs during an admission to hospital. Family carers of people with dementia often report that they are not properly involved in preparations for discharge from hospital. These audits have also highlighted major differences in the quality of care that hospitals deliver for people with dementia. But very little is known about why some acute hospitals can provide higher quality of care to people with dementia than others.

Objectives

- To identify features of wards and hospitals that are associated with higher quality of care and shorter length of admission for people with dementia.

- To understand how aspects of the organisational form and function of hospital services impact on the quality of care that people with dementia receive.

- To examine how contextual factors including organisational culture can support and/or impede the delivery of effective care.

- To make recommendations about the optimal organisation and delivery of acute hospital care for people with dementia.

Methods

This was a mixed methods study comprising two work packages. In work-package one, we conducted a secondary analysis of data from the third round of National Audit of Dementia

and the second national survey of Liaison Psychiatry services in England. In work package two we conducted qualitative interviews with senior managers, front line staff and family carers across six study sites in England. We selected these hospitals based on their performance in the National Audit of Dementia. Prior to the start of the study we conducted a scoping literature review to ensure that the study built on the results of previous research in this field.

Work package one

The National Audit of Dementia is designed to assess the quality of care delivered by all acute hospitals in England and Wales. The third round of audit collected data between April and November 2016. We used data from three components of the audit: a hospital level organisational checklist; a retrospective case note audit with a target of a minimum of 50 sets of patient notes of patients who had been given a clinical diagnosis of dementia and been admitted to hospital for 72 hours or longer; and a survey of carer experience of quality of care. The second national survey of Liaison Psychiatry services aimed to collect data on the provision of mental health liaison services at all acute hospitals in England that include an emergency department.

Following a review of extant literature and consultation with stakeholders, we selected process measures from those collected by the audit and examined associations between these measures and the three study outcomes: length of stay, carer-rated quality of care and quality of assessment of patient needs. As part of the audit a paid or family carer was asked to rate the quality of care that each patient received using a validated measure of carer experience. We used the hospital scores for the single item question 'Overall, how would you rate the care received by the person you look after during the hospital stay?' on this measure. The scores were calculated per hospital based on the individual score and the total number of carer respondents. The measure generated a total score on a continuous scale from zero (low carer rated quality of care) to 100 (high carer-rated quality of care). Data from clinical records were used to assess the quality of assessment that each patient received. Each patient received a score from zero to seven according to whether they had documented evidence of having been assessed for mobility, nutritional status, pressure ulcer risk, continence needs, presence of any pain, functioning, and delirium.

We explored the relationship between dependent variables (carer-rated quality of care, quality of assessment and average length of stay) and patient-level (age, gender, ethnicity, presenting complaint), ward level (type of ward), and hospital level (access to liaison mental health services, deployment of specialist dementia nurses, involvement of the Trust Board, etc.) predictor variables using multivariate analysis. Given the nested structure of the data (patients within hospitals), the final analysis was carried out using Hierarchical Models. Unlike length of stay and quality of assessment which were measured at the patient level, carer-rated quality of care was measured at the hospital level. All variables needed to be aggregated at hospital level for this analysis. We obtained patient-level data on demographic and clinical characteristics of patients together with information about the type of ward(s) where the patient was treated and hospital-level data on aspects of the organisation and delivery of care that may influence the quality of care that people receive.

Work package two

Work package two consisted of six comparative case studies of dementia care in acute hospitals. We selected our study sites based on their performance and governance infrastructure scores in the National Audit of Dementia to compare pairs of hospitals that organise and deliver care in a similar way but achieve different outcomes. To optimise the contribution of work package two to the study we designed and implemented a 'twin track' approach to theory development; Track A: Qualitative exploration of factors associated with patient outcomes in work package one, and Track B: Theory testing and refinement (realist evaluation).

We used purposive sampling to interview a diverse range of staff, from a range of professional backgrounds and seniority, with/without managerial responsibilities. With the help of staff, we also identified and interviewed several family carers. We developed separate topic guides for staff and carers and shared them with members of the Project Advisory Group for their comments. The topic guides were designed to be used flexibly to allow researchers to be responsive to issues raised by participants. With consent, interviews were digitally recorded and transcribed. Interview transcripts were coded in NVivo Pro 11 using a coding scheme developed by the study team.

We used a thematic analysis approach to analyse the qualitative data. In Track A, we explored some of the associations found in work package one. For example, we found that initiation of discharge planning within the first 24 hours of admission was associated with shorter length of stay, so we were interested in finding out how and why that might be the case. In Track B, we used a realist approach to refute and refine programme theories we developed at the outset of our fieldwork. A decision was made to focus reporting of Context-Mechanism-Outcome (CMO) configurations for two main areas of interest: staff dementia training, and carer involvement.

Results

Results of our scoping review of the literature identified seven key themes that influence the quality of acute care for people with dementia: *care environment*, *cultures of care*, *attitudes*, *challenges for people with dementia as an acute patient*, *challenges for carers*, *challenges for staff*, and *service models*. These results informed our decisions about which predictor variables to include in our analysis of audit data. They were also used to help draft the content of the topic guides for qualitative interviews in work package two.

Work package one

Two hundred (98.5%) of 203 acute hospitals in England and Wales took part in the audit. All 200 hospitals submitted an organisational checklist. Data from the clinical records of 10,106 patients were also submitted and 4,688 carer questionnaires were received. Data on provision of mental health services were obtained on 176 (88%) of the 200 hospitals that took part in the audit.

The median length of stay was 12 days. The median length of stay varied between different hospitals and ranged from five to 39 days. In the multivariate analyses, ethnicity of the patient, presenting condition and ward type were associated with length of stay. BAME patients had shorter length of stay, patients presenting with respiratory conditions had shorter admissions compared to other conditions, and patients on care of the elderly wards had a higher average length of stay compared to those on general medical and surgical wards. When discussions with carers were recorded in case notes patients had a longer average length of stay. When there was documented evidence that discharge planning had been initiated within 24 hours of

admission patients had shorter average lengths of stay. In hospitals where the liaison teams included an old age consultant psychiatrist, shorter lengths of stay were found in the records of patients where there had not been a discussion with the responsible consultant. There was a non-statistically significant trend towards patients having shorter average lengths of stay in hospitals where Trust Boards regularly reviewed delayed discharges.

Regarding carer-rated quality of care, we found that hospitals that had a carer strategy in place had lower levels of carer satisfaction. There was a non-statistically significant trend towards hospitals which had greater availability of personal information about patients on wards having higher levels of carer-rated quality of care. This association was statistically significant in hospitals with higher proportions of patients and carers from BAME communities.

We found that ward type, age of patients, and length of stay all influenced the quality of assessment that patients received with more comprehensive assessments being documented for older patients, for those who were in hospital for longer and for those admitted to care of the elderly wards. Among patients who had longer admissions higher quality assessments were recorded for patients in hospitals that deployed greater numbers of dementia specialist nurses.

Work package two

In total, we conducted 63 interviews across six study sites, comprising seven carers and 56 staff. Staff working in acute hospitals told us that, whilst early discharge planning is important to decrease admission length, factors such as complexity of patient needs impede the effectiveness of discharge planning within the first 24 hours of admission. Staff mentioned systems in place for escalating concerns when obstacles to discharge arise, including holding daily multidisciplinary team meetings and named staff taking responsibility for coordinating the person's discharge. Staff confirmed that when Trust Boards review delayed discharges, they can identify recurring problems and work with local authorities and commissioners to try to resolve them.

Staff believed that family carers play an important role in supporting provision of high-quality care for patients with dementia. The presence of family carers allows patients to settle as carers are better able to make patients feel at home by following the routines that patients are

used to. Lack of family carers also means that hospitals are required to organise more social care upon discharge which means patients might stay longer in hospital than they need to. However, involving family carers might lead to dissatisfaction in situations when they have unrealistic expectations about what hospitals can provide and/or when detailed information about personal preferences of patients are collected by staff, but care is not delivered in accordance. Disagreements about the time and plan of discharge can give rise to further contentions which potentially leads to longer hospital stays. Clear communication with and involving family carers from early stages mean that they are more likely to form realistic views about what acute hospitals can and cannot provide.

Staff from a range of professional backgrounds and seniority, told us that dementia specific training plays an important role to ensure patients with dementia receive high quality care. Staff also made comments about how and why dementia training would lead to better outcomes. Factors associated with better outcomes include mandatory dementia training for existing and new staff members, in house training delivery, and an internal audit system to evaluate the effectiveness of training. The presence of educators on the wards who can role model best practice helps staff to make a better sense of theoretical taught materials. When training material includes simulation sessions, it helps staff to empathise with what a patient with dementia might feel which leads to more humane care.

The culture of the hospital and attitude of senior staff have a great bearing on the quality of care patients receive. In hospitals where staff feel valued, supported and empowered to exercise a certain level of autonomy, patients receive a more humane and person-centred care. In these hospitals, task-oriented practice is discouraged, and staff are encouraged to ask questions and share the challenges they face.

Conclusions

It is important that hospitals make greater efforts to ensure that discharge planning is initiated within 24 hours of admission for all patients with dementia. Steps could be taken to increase the availability of personal documents on all wards where people with dementia are treated. If front line staff communicate with carers early on, they can ensure that concerns are identified and help carers develop realistic expectations about what can be achieved during the admission.

We recommend that future research be undertaken to identify policies and practices that reduce inpatient admissions among people with dementia by providing high quality acute care in the community. Methods for enhancing carer involvement by co-producing optimal care packages and co-delivering dementia training for staff could also benefit from further research. Future research could explore our unexpected finding of differences in the quality of care and length of stay in patients with dementia from BAME backgrounds. We could not fully explore the negative association between hospitals having a carer strategy and carer satisfaction. It would be helpful if future research explored this further with a focus on the relationship between intention, execution and organisational culture.

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