

Identifying factors contributing to acute hospital delayed discharge for people living with dementia

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Introduction

At least 25% of general hospital beds are occupied by people living with dementia. On average people with dementia stay more than twice as long in hospital than other patients aged over 65. Evidence shows that longer hospital stays for older patients can lead to worse health outcomes and an increase in their care needs on discharge.²

Supporting a reduction in patients having a delayed transfer of care (DToC) is a priority for the NHS. The Five Year Forward View Next Steps document highlights that hospital primary and community care and local councils should work together to ensure people are not waiting in hospital due to DToCs³. The high impact change model⁴ has been developed to support a reduction in DToCs and made recommendations such as 'discharge to assess'.

DToC data is published monthly by NHS England⁵. In June 2018 there were just over 14,000 DToC bed days across London Trusts. The three commonest causes were; awaiting nursing home placement or availability (2618), awaiting further non-acute NHS care (2600) and patient or family choice (2066). DToC data lists the number of delayed bed days per Trust, CCG and by reason. However, it does not tell the story behind the delay and does not include discharge delays which are not formally a DToC e.g. someone who is medically fit and awaiting acute therapy input.

The aim of this project was to better understand the factors contributing to delayed discharges from hospital for people living with dementia through a detailed case note analysis.

Methods

The 26 London Directors of Nursing (DoN) of acute and community hospital Trusts were invited to take part in the project. Twelve (46%) expressed an interest to take part. Two reviewers visited each participating hospital. Staff were asked to identify one or two patients with cognitive impairment or dementia who were either designated as a 'delayed discharge' or perceived to be difficult to discharge. The reviewers conducted in-depth case notes reviews including medical, bedside notes and any community notes when available. The reviewers also gained insight from ward staff on discharge delays. A semi-structured proforma, based on root cause analysis principles, was used to standardise the information collected.

Specific feedback was given to each participating hospital. Case note reviews and staff experience from across the hospitals were anonymised then jointly reviewed and themed. In addition, a workshop was held for discharge coordinators across London in September 2018 to triangulate findings and prioritise recommendations.

Results

Ten hospitals were visited including acute and two community sites and sixteen sets of notes were reviewed. Insights were gained from staff from a range of backgrounds including medical, nursing, discharge coordinators, occupational therapy, physiotherapy, care home management and hospital management.

Five main themes were identified. These were; rehabilitation potential, clinical history, documentation, joint working and supporting family involvement. There were also two key areas noted specific to dementia; missed diagnoses and managing behavioural and psychological symptoms of dementia in care homes.

Rehabilitation potential

Rehabilitation potential can be difficult to establish, particularly for people living with dementia and it is not always appropriate to ascertain in an acute hospital environment. Staff reported that there was sometimes a lack of senior therapists to help support decision making and that sometimes there was a risk averse and over cautious approach to home discharges. Staff also reported that some families had unrealistic expectations of rehabilitation.

In some of the cases reviewed, there was clear documentation of when progress was not being made and when a new functional baseline had been established. This supported the MDT to make prompt discharge plans and facilitated conversations with families. In other cases, there was a lack of documentation about rehabilitation potential and discharge plans did not always seem to match progress being made with therapy. Some cases also demonstrated a lack of ongoing conversation about progress with therapy, which led to families being surprised and distressed about a new functional baseline. Often rehabilitation potential was not reviewed in relation to patient's goals.

Clinical history

Gaining a good clinical history on the lead up to admission, and the picture over the last 6 months appeared to support the discharge process. In some cases, a clear history of functional decline was only established once someone was medically fit for discharge. This information ultimately changed the discharge plan and subsequently delayed the discharge. In other cases, a six month history was identified from relatives and community clinical teams on the first few days of admission, which subsequently facilitated earlier accurate discharge planning.

Documentation

Some hospitals used paper based notes and others electronic notes. When notes were all in the same place and discharge planning was clearly highlighted, such as using a discharge sticker, discharge plans and joint MDT working were clear. In some cases there was very minimal discharge planning documentation and in these cases it felt that plans were not being chased e.g. a package of care start date. In one hospital the social worker also documented in the medical notes which improved the clarity of the discharge plans very clear.

It was extremely useful when notes from other clinical systems were able to be accessed e.g. RIO notes from the community mental health team, but this was often reliant on a member of staff who worked across organisations having access to these records. In one case useful notes from the care home had not been scanned onto electronic systems which would have aided a clear presenting history and supported discharge planning. The discharge coordinators also highlighted that some staff need protected learning time to improve IT literacy.

Differing approaches to documenting capacity assessments was found. In hospitals that used a template, assessments were very clear, in hospitals that did not (e.g. documented as part of ward round) there were sometimes unnecessarily repeated assessments, and disagreements between members of the MDT.

Staff reported that there was often a delay in completing discharge paperwork (e.g. district nursing referrals) as clinical tasks needed to be prioritised. The workload challenges had an adverse impact on staff completing tasks that would enhance discharge. Where Trusts had invested in additional discharge coordination roles, which led on discharge and released ward staff, paperwork was completed in a timely manner.

Joint working

Some Trusts reported positive input from social services and said that they were an integral part to the ward multidisciplinary team. In other areas communication between the hospital and social services appeared to have broken down leading to a 'blame culture'. In one hospital relationships were being built with local care homes which led to a better understanding of services, which supported discharge planning. Whilst relationships between social care providers and health providers were evident, communication was often via email or phone. Where health staff had successfully managed to meet care home or social care staff face to face or they shared offices, communication was improved, and they reported that smoother discharges occurred.

One hospital had additional healthcare assistants who were working on patient flow and supporting discharge planning, the ward staff had a poor understanding of their role leading to confusion and duplication of work. In contrast other Trusts who had additional staff to support discharge embedded them within the discharge team which appeared to support timely discharges.

The discharge to assess process had become confused in some areas. The pathway for completing continuing health care paperwork between the ward and continuing healthcare teams had also become confusing, in one case paperwork took nearly two months to complete.

From discussing with acute and rehabilitation staff, it was evident that there was sometimes a lack of understanding of each other's priorities and roles which led to negative communication and a lack of trust. Rehabilitation staff felt that sometimes inappropriate patients were admitted for rehabilitation and that patients' abilities and rehabilitation potential were sometimes exaggerated, and acute hospital staff felt that sometimes the referral criteria for rehabilitation were too strict. Long waits in some areas for assessment and admission to neurorehabilitation services were also highlighted.

Supporting family involvement

Frequently, the hospital team spent a considerable amount of time with family members and thorough documentation of family meetings was noted, in several cases it appeared in hindsight that it would have been better to have held an earlier family meeting e.g. when a patient was not making progress with therapy.

In some cases the family was not involved in completing the continuing healthcare checklist, which led to later queries and concerns, and subsequently delayed the discharge. Staff reported that sometimes it was difficult for families to visit to complete checklists jointly, discussing on the phone was used as an alternative.

Staff often reported family delays including; families not aware of the cost implication of being a self-funder (there was a presumption that social services funds everyone), going on holiday when someone is admitted, refusing to accept equipment and different family members disagreeing on discharge plans.

Trusts had discharge policies in place for when appropriate, to ensure medically fit patients were discharged to an appropriate site. It was clear that senior leadership was required to implement these policies and ward staff did not always feel supported to hold these very challenging conversations. It was reported that if 'choice letters' were given to families / patients too soon it could have a negative effect on relationships.

There was a lot of discussion from staff on the best time to give an estimated discharge date, some colleagues felt it was appropriate to do in A&E and others found that this was too soon, and the date often was changed, which led to unnecessary difficult conversations with families. There was a consensus that information should be given in A&E, however this may need to be more generalised e.g. expectations around discharge once medically fit, rather than a specific estimated discharge date.

Missed diagnoses

We found several cases where a patient did not have a formal diagnosis of dementia and yet had clear clinical signs and symptoms of dementia. In one case the Parkinson's clinic reported that they felt that there was probably an underlying dementia. In another case it was ascertained from community notes that the patient had had an assessment in the community and it was felt he did have dementia, but the diagnosis had not been formally recorded. In one case a patient had been a resident in three different care homes and had a long history of cognitive impairment and was diagnosed with dementia in the acute hospital.

Behavioural and psychological symptoms of dementia

Several cases highlighted difficult discharges for people with behavioural and psychological symptoms of dementia. Patients with stable behaviours that challenge were admitted from care homes with no acute medical issues and care homes were not able to accept residents back. Patients were not able to return to their care home when needs increased, for example worsened mobility or needing assistance with eating and drinking. In one case twelve care homes declined admission before a care home was found.

Discussion

The methodology of this review enabled a more qualitative understanding of some reasons behind delayed discharges. Only a small number of cases were examined and in most cases there was no access to community notes to complete the picture, however similar themes emerged across the hospitals which will support understanding of delayed discharges.

It was important to include cases where staff perceived the patient has a cognitive impairment as well as cases where the patient had a diagnosis of dementia, as several of the case studies represented patients who appeared to have had dementia, but no formal diagnosis. This is an important consideration for similar projects.

The case notes reviews and discussion with staff have highlighted some key areas which contribute to delayed discharges, which would not have been highlighted from DToC data. It appears that some relatively small changes could be made to support reducing delayed discharged for people living with dementia.

Clear documentation on rehabilitation potential in relation to goals and early family meetings appeared to support timely discharge planning, services may want to consider reviewing their local practice.

Gaining a six month clinical history also supported a timely discharge, services may want to consider how this information is ascertained and how it can be established as soon as possible. Discharge coordinators highlighted one of their top recommendations from the project findings should be to ask 'who is the key contact for the patient' in A&E (person who knows patient best) and gather key information using a proforma.

Simple steps can be taken to make discharge planning documentation clearer, for example, putting a sticker in paper notes or writing 'DC PLANNING' on computer notes. Staff documenting in the same place in notes also made plans clearer.

Integration and joint working is frequently discussed, it is important that it also feels integrated. Facilitated meetings between ward staff and key community services such as social care and intermediate care may be required to help build relationships.

Staff need to be supported to hold emotionally sensitive conversations around discharge planning. The new dementia NICE guidelines state that 'health and social care professionals advising people living with dementia should be trained in starting and holding difficult and emotionally challenging conversations'⁶. Trusts may want to consider how they can support staff in holding these conversations.

This project has also highlighted some key areas to consider outside hospital care. There needs to be a continued drive to improve dementia diagnosis rates, it is currently predicted that there are nearly twenty thousand people living in London with dementia and without a diagnosis⁷, without a diagnosis people are unable to access post-diagnostic support which can prevent crisis and hospital admissions.

This project has also highlighted that care homes need support to provide the best care for people with behavioural and psychological symptoms of dementia. NICE guidelines state that services should 'offer psychosocial and environmental interventions to reduce distress in people living with dementia'⁶. Support for care homes needs to be reviewed from a commissioning, health and social care perspective using the enhanced health in care home framework⁸

Conclusions

This project has highlighted the importance of understanding the stories and reasons behind delayed discharges. True joint working, clear documentation, gaining a six month history and supporting staff with holding emotionally sensitive conversations will help to support a timely discharge.

The Clinical Network is planning on working with two hospitals to implement some of the considerations from this project

We would like to thank the hospitals that participated in this work and the staff who shared their expert insights.

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