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Meeting the needs of patients with dementia to reduce hospital stays: a qualitative exploration of patient pathways and services

Abstract

Background

This study formed part of a project investigating the impact of providing care to patients living with dementia on acute services across England.

Aim

It aimed to gain a better understanding of how to meet the needs of patients and identify areas of good practice across England.

Methods

Qualitative interviews were undertaken with 42 professionals within five areas of England, and a focus group with 7 carers.

Findings

Working practices to support patients living with dementia and their carers vary significantly by geographical area. The study identified many examples of good practice in preventing hospital admission, admission to hospital, hospital stays, discharge from hospital and post-discharge provision.

Conclusion

Different working practices have resulted in a lack of consistency in the provision of and access to services for patients with dementia as well as gaps in provision. However, a range of good practice examples were identified.

Background

With improved public health measures, people worldwide are living longer lives, leading to an growing ageing population that has a greater risk of health conditions such as dementia, a term for several diseases that affect thinking, reasoning, remembering and the ability to perform daily activities.

In the UK its estimated that there are 944,000 people living with dementia, predicted to rise to 1.6 million by 2050, with estimated costs of £25bn, expected to double to £47bn by 2050 (ARUK, 2023). Two-thirds of this is paid by people living with dementia and their families through either unpaid care or paying for private social care, with a third attributed to the provision of social care and medical care (Alzheimer's Society, 2023). Supporting and caring for people living with dementia is a key priority in England and is one of the 10 priorities identified in NHS England's *'Five Year Forward View'* (2017) and one of the six priorities identified in the UK Government's Major Conditions Strategy (DHSC, 2023).

Estimates suggest that one in four acute hospital beds are occupied by patients living with dementia and a fifth of the admissions are for preventable conditions (Alzheimer's Research UK (ARUK), 2023). People living with dementia are admitted to hospital more frequently than those without dementia (Wolf et al., 2018; Shepherd et al., 2019) and readmission to hospital is higher (Pickens et al., 2017; ARUK, 2023). They have higher hospital mortality rates and longer hospital stays than patients who do not have dementia (Fogg et al., 2018; ARUK, 2023) and often experience delays in being discharged from hospital (ARUK, 2023).

Admission to hospital can be both harmful and distressing for people living with dementia as they commonly experience functional decline during their admission (Dewing & Dijk, 2016; Featherstone et al., 2019). Other negative outcomes may include spatial disorientation, an increased likelihood of falls, potential malnutrition and dehydration, depression, higher incidences of delirium, and an increased reliance on carers (Dewing & Dijk, 2016). Carers of people living with dementia regard changes and deterioration in the person's condition as being due to care received during their admission, specifically negative outcomes from what staff did

or failed to do (Dewing & Dijk, 2016). Rao et al (2016) found that following discharge from hospital, people living with dementia are vulnerable and prone to further complications as they recover more slowly from illness, experience loss of mobility and are residing in nursing homes.

Aim

This qualitative study formed part of a wider project investigating the impact of providing care to patients with dementia on NHS acute services across England. The aim was to gain a better understanding of how to meet the needs of people living with dementia in the context of acute services and identify areas of good practice across England. This paper reports on the primary qualitative findings only.

Methodology

Secondary data analysis (used to identify the locations for interview)

An analysis of Hospital Episode Statistics (HES) by Clinical Commissioning Group (CCG) areas across England was undertaken in February 2019. This secondary data analysis looked at data for people living with dementia over 65 and a control group of people without dementia over 65, covering a ten-year period. Gender and age group breakdowns (65-74, 75-84 and 85+) for a number of metrics were included. The data analysis used this information to develop metrics to highlight variations between areas, specifically:

- Cost per spell.
- Length of stay.
- Excess bed days as a proportion of total bed days.
- Spells per patient.
- Proportion of the total estimated dementia population admitted annually.
- Proportion of all spells that were non-elective.

Primary qualitative research

A shortlist of areas with better patient outcomes was produced and used to inform the qualitative phase of the study which explored the working practices of five of the areas that were performing well based on the HES data. Areas were selected to provide a range of population spread (urban, rural and mixed) and geographical locations spread across England. Areas 1 and 5 covered an urban area. Areas 3 and 4 covered mainly rural areas with a number of large towns. Area 2 covered an almost entirely rural area.

Face-to-face interviews were undertaken with representatives from local authorities, clinicians and NHS commissioners, and a focus group with carers, between May and August 2019.

Recruitment

The relevant Dementia Clinical Networks were contacted, and their support enlisted to obtain introductions to key clinical leads and commissioners within each area. The researchers then recruited professionals in each locality partially through direct email requests (where individuals were introduced to the research team) and partially through snowballing (where the initial contact introduced the researchers to others within their area). The selection of potential participants was based on their involvement in running or developing services and support for people living with dementia.

An email/letter was sent to all members of an existing “sounding board” of carers of people living with dementia, inviting them to take part in a focus group.

A Participant Information sheet was provided to all participants and written consent was obtained before the start of the interviews/focus group.

Participants

Interviews with a total of 42 professionals in the five locations were conducted between May and August 2019. The job titles of those interviewed were:

Associate Director/Director	of mental health services, nursing or CCGs
Head of Integrated Care or	within CCGs

Mental Health Services	
Commissioner	within local authorities and CCGs
Dementia Lead	in local authorities
Clinician/practitioner	including clinical psychologists and dementia specialist nurses
Consultant	in hospitals and mental health trusts
Lead Practitioner	for care homes or hospital discharge/assessment
Care Home Lead	
Memory Assessment Practitioner/Team Manager	within older people's mental health services
Project Manager/Service Manager/Team manager	for older people's services, older people's mental health services or a dementia intensive support team
Care Navigator/Team Manager	in the voluntary sector

The focus group comprised seven carers, all partners or children of people living with dementia.

Analysis

The interviews and focus group discussion were recorded, transcribed and analysed using thematic analysis (Braun & Clarke, 2006) by the interviewer, in collaboration with the principal investigator. A thematic coding framework was developed following familiarisation with the transcripts and broadly followed the interview guide. Interview content was first allocated to each part of the pathway and then coded under three broad themes:

1. Issues and challenges identified.
2. Current practices in the interview location including examples of good practice.
3. Good practice planned and known about in other locations.

In addition, examples provided were identified as being specifically relating to people living with dementia, support for families and carers, or services for all patients, not just those with dementia.

Ethics

Ethics approval was granted by the University of Essex's Faculty Research Ethics Committee (reference: 18010). The relevant research governance contact was approached to give approval to interview all professionals employed by an NHS Trust, before they were invited to take part in an interview.

Findings

Findings from the interviews and focus group combined are presented under five points on the patient pathway: (i) prevention of admission to hospital; (ii) admission to hospital; (iii) the hospital stay; (iv) discharge from hospital; and (v) post-discharge provision. Finally, several systemic challenges are summarised as identified by the participants.

1. Prevention of admission to hospital

There appeared to be some degree of variation (or "postcode lottery") in the preventative support and healthcare services accessed by people according to their level of affluence and/or rural locations.

> *"The haves are the affluent ones, they're very resourceful, they seek care, they ask for the support when they need it and they get it. The have nots actually we might not even see them in the community at all… what tends to happen is by the time they come to the attention of services they are extremely acute." (Interviewee in Area 5)*

Additionally, the three non-urban areas identified that different practices within their county and/or neighbouring counties (for people living on the borders) led to inconsistency in the provision of and access to services. The two urban areas highlighted issues within certain

ethnicities and cultures in terms of stigma, equitable services and the provision of culturally diverse services.

Gaps were identified in service provision, for: people with early onset dementia, mild cognitive impairment, and learning disabilities and dementia; dementia specific respite care and supporting carers; and out of hours' crisis support.

Several areas had Admiral Nurses[1] in place, although ongoing funding was short term and sometimes reliant on local fundraising. There was a range of voluntary sector provision of community-based services, some being dementia-specific and others universal. Two areas had a range of dementia support within the community and had moved away from day centre provision to a more enabling and community-based provision.

Participants mentioned devices, digital care and assistive technology solutions that could be provided to enable people living with dementia to live at home for longer and more safely. These included: geo-locator devices; sensors that can look at patterns of movement; alarmed carousels for medication; memo minders or pager type reminders; pressure mats before doors, possibly with an alarm to alert someone when it is stepped on; pressure sensors on beds where changes trigger an alert; and responder services to a call alarm or alert.

Areas facilitated mental health liaison services in the community in different ways, but they usually had a dementia specific element. Some areas had a single point of entry and some were able to provide intensive short-term support for people in their own homes.

All the areas provided specialist dementia support to care homes and their staff, but in different ways and with a different level of resourcing.

Four areas had an intensive support team to provide care or support for all people (with and without dementia) to avoid admission/readmission to hospital or a care home. Several hospitals had an early intervention or rapid response service to provide care and support to prevent hospital admission or rapidly get people out of their assessment units. Two hospitals had a

[1] As a service provided by Dementia UK, Admiral Nurses are registered nurses with experience in dementia care who work collaboratively with families and with other dementia care providers. They provide expert practical, clinical and emotional support to families living with dementia.

‘virtual ward’ which was run by community matrons to try and avoid admissions. Two areas had an intermediate care service that was used to prevent hospital admissions as well as for discharges. However, just three of the areas had these types of intensive services that were specific to people living with dementia.

2. Admission to hospital

One issue faced by a number of areas was the (national) shortage of mental health acute beds, especially for patients in a crisis. Another issue was the absence of a ‘patient story’ and information about someone on admission. Several hospitals acknowledged that they did not currently screen well for delirium or dementia, although two highlighted the use of a cognitive screening tool or frailty assessment. Area 5 aimed for earlier assessments/identification of people living with dementia within Accident and Emergency (A&E).

NHS risk management policies meant that hospital staff tended to take *“the safer route”* when patients with dementia presented at A&E so might admit someone with dementia whereas they would not admit a patient without dementia with the same symptoms.

Most areas - but not all - had specialist wards within mental health trusts for patients with dementia and distressed behaviours or complex needs. Since the number of beds was usually low, these patients might be admitted to other mental health wards or wards in acute hospitals. One mental health trust reported they had reduced the demand for these beds through building connections with the referring mental health workers and encouraging them to explore options other than *“containment”*. Some acute hospitals had wards specifically for dementia patients, but not all. When one hospital had to use general wards for patients with dementia and distressed behaviours, they tried to put some extra provision in such as 1:1 staffing for the hospital stay.

Many areas mentioned the 'This is Me' document[2] or an equivalent and talking to family members in terms of obtaining information about people living with dementia. One hospital had a shorter pictorial version of this. However, many patients did not have this type of document completed prior to their admission.

The Red Bag Scheme[3] for care home residents was used in many areas, although bags were often not returned to care homes afterwards and awareness of their purpose was sometimes lost over time.

3. **Hospital Stays**

The main issue for people living with dementia staying in hospital was seen as the ward environment since older adult wards were generally not felt to be good environments for people living with dementia, and the ward environments or layouts were often not dementia friendly.

> *"People also miss how unsettling going into hospital is. It's like a busy, unfamiliar environment, where they don't really get any sort of meaningful support." (Interviewee in Area 1)*

Good practice was identified around making wards dementia friendly (physically in terms of signage, colour, outside areas etc. or ways to identify patients with dementia such as forget-me-nots) and providing a range of meaningful activities for patients (such as reminiscence work, music or art) to keep them engaged and active.

In several areas, the support from dementia specialist practitioners provided to professionals on the hospital wards and in A&E was seen as very valuable. Specialist advice was provided to hospital staff in various ways including: a specialist dementia practitioner trainer, a psychiatric liaison service, a lead nurse or staff based on the ward dealing with a high proportion of patients with dementia who share their expertise.

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[2] 'This is me' is a simple leaflet for anyone receiving professional care who is living with dementia. It can be used to record details such as their cultural and family background, important events, people and places from their life and their preferences and routines.

[3] The red bags - containing key paperwork, medication and personal items like glasses, slippers and dentures - are handed to ambulance crews by carers/care home staff and travel with patients to hospital where they are then handed to the doctor.

Support for carers was important with several hospitals having a carers' passport and/or being signed up to John's Campaign[4] – although this was not necessarily being implemented and ward staff were not always aware of it. Some hospitals tried to invite families to participate in their planning meetings for patients while one provided support specifically for carers.

> *"I think that's so important is that someone, a family member or whoever it is recognised as an expert… that's got to be recognised by the healthcare professionals." (Husband in carers focus group)*

4. Discharge from hospital

All the areas stated that discharge planning for all patients (not just those living with dementia) started almost at the point of admission, or as early as possible. Most had robust Delayed Transfers of Care (DTOC) processes for all patients, but reported that patients with dementia (and especially those with complex issues) were likely to have a higher number of DTOC days compared to someone who had depression.

Several areas had a dementia specialist working with or within the hospital discharge teams for patients with complex needs, or a specific team for these patients. Multi-disciplinary working was seen as highly important to make the discharge planning process effective, with some areas highlighting the positive impact of teams being co-located and mental health liaison being seen as very important to support the discharge of patients with dementia.

Interviewees in Areas 1 and 5 were positive about the care brokerage teams based within their local hospitals and funded by social care (for all patients).

Two hospitals had a 'virtual ward' for all patients where staff visited people in the community after discharge to make sure they were managing and to check on medical issues. Some interviewees were very positive about the Discharge to Assess model[5] although there were

[4] John's Campaign calls for a policy welcoming family carers onto the wards outside of the normal visiting times, according to the needs of the person with a dementia and not restricted by stated visiting hours.

[5] Discharge to Assess supports patients who are clinically stable but need further assessment of their ongoing health and social care needs to leave hospital.

barriers for people living with dementia to follow this pathway and one area reported that few patients with dementia went through this pathway.

Several areas highlighted the importance of building good relationships with care homes, and a consequent level of trust, which was key to ensuring the smooth discharge of patients there. A number had care home liaison teams that also acted as trusted assessors[6], a role that was highly valued and that expedited discharges since patients could wait quite a long time to be assessed to go to a care home that had not signed up to the trusted assessor scheme.

A number of areas actively involved families in the discharge planning process and tried to have open conversations with them about options on discharge and/or long-term care.

5. Post-discharge provision

Across all the areas, there were reports of a lack of provision of transitional, step down, assessment and care home beds for patients with dementia, especially those with distressed behaviour or complex needs, which could lead to delays in discharge. Access to intermediate care and assessment beds had produced good outcomes for patients discharged there, but there were too few intermediate care beds.

Several areas highlighted they did not have a robust pathway for discharging patients with delirium and/or dementia.

Several areas identified that delays in arranging care packages or carrying out assessments (including by care homes) could delay discharges.

> *"Sometimes capacity is a problem, in terms of they actually can't take the patient today, even though they're ready to go, because they can't put the care in." (Interviewee in Area 5)*

One area reported they had no dementia specific providers for domiciliary care. Another highlighted delays in obtaining care packages or equipment for people's homes that could delay their discharge. Two of the rural areas reported challenges sourcing domiciliary care (even for

[6] 'Trusted Assessor' schemes aim to reduce delays when patients are ready for discharge and is based on providers adopting assessments carried out by qualified 'trusted assessors' who work under a formal, written agreement.

patients without dementia) due to the long travel times. One area felt that reablement and/or physiotherapy were very limited and not often available to patients with dementia. A challenge for several hospitals who had patients from other administrative areas was that the other areas worked differently to the one they usually dealt with.

> *“The difficulty with the different borders is the different systems that are in place, that are the same teams with a completely different name. It can be a bit of a minefield determining which services to use."*

Several areas were able to quickly put into place short term personal and/or nursing care packages to enable all patients to be swiftly discharged home while waiting for permanent packages of care to be authorised. This had either reduced the length of hospital stay or reduced DTOCs. Additionally, for all patients, some areas had a form of step-down support in the community after discharge. Some areas used the voluntary sector to provide support to all patients who just needed a small amount of support to return home. However, people living with dementia were less likely than others to receive these types of services.

Most areas had intermediate care or transitional beds within care homes for those who were medically optimised but not yet fit to return home. These were usually supported by a care home liaison team and/or a community multi-disciplinary team. Area 4 said few patients were discharged into intermediate care beds since their observation bay in A&E could start to reverse an acute episode within 24-48 hours and also because their community services were very successful in patients returning back to where they were living before. Area 1 paid a dementia premium to support care homes to manage people living with dementia while Area 5 had upskilled care homes to be able to receive them back more quickly.

All of the areas highlighted the increasing demand for, but lack of capacity in, the care and nursing home sector for people living with dementia with distressed behaviours.

The pressures generally facing care provision exacerbated the difficulties in keeping people living with dementia out of hospital or discharging them quickly. Pressures not already identified

included: inconsistency in the practices of care agencies or variability in the quality of care; some care agencies no longer accepting social care rates; workforce issues for care/nursing homes in terms of staff recruitment and retention; and lack of respite provision.

6. Systemic challenges

Awareness of dementia appeared to be extremely variable across different professional groups and within different organisations. Raising awareness needed to be a continuous process and embedded across services, to avoid a decrease in awareness if a key member of staff, such as a dementia champion, leaves. Most hospital staff had at least a basic level of dementia training within induction but the levels of awareness amongst GPs was variable and GPs were not always aware of next steps or confident about supporting someone living with dementia. Training for domiciliary care staff and care home staff was variable and, given the turnover of staff, raising awareness and training had to be a continuous process.

Carers in the focus group wanted a person-centred and holistic approach to services, rather than their loved ones being treated as separate parts, and this was reflected by a number of professionals.

All areas identified multi-disciplinary working, if not integrated working, as being key to improving outcomes. Several participants felt that while there could be tensions between health and social care around budgets, front line staff worked very well together especially where there were joint and multi-disciplinary approaches. Most areas had a dementia forum or reference group in place, which was effective in bringing everyone together.

> *“Those key players sitting in a room and talking about their interfaces and letting each other know what they can and what they can’t do… And I think just by knowing each other not only by name but by face has made a huge difference." (Interviewee in Area 5)*

Many areas highlighted lack of funding as an issue, especially for social care but also increasingly for health, with the added pressure on resources caused by the increasing demand on services due to the growing number of people living with dementia.

All areas highlighted issues with IT systems and data sharing between different health and social care organisations. Health and social care staff used separate systems for case management that did not communicate with each other so that there was a great deal of dual inputting and telephoning other organisations.

Area 4 was piloting a *Population Health Management* intelligence system that used data to identify people proactively before they reached a crisis. It was thought that potentially this would have an enormous impact on transformational type change. The system records data from various different sources (matched by NHS ID number) converting it into datasets with different levels of access.

Discussion

It is crucial to implement a dignified, person-centred approach to care focusing on the unique situation of each individual (ADI, 2022; Beardon et al., 2018). However, Røsvik & Rokstad (2020) acknowledged the need to improve hospital staff's competence in person-centred care and managing patients living with dementia. Participants in this study advocated treating people living with dementia in a holistic, person-centred way, including improving processes to involve families/carers.

Supporting families and friends with a caring role is very important as people living with dementia, their carers, and professionals form an important triad within a care relationship that requires equilibrium to thrive (ADI, 2022). This study highlighted the variance of the support currently available for people living with dementia and their carers, including support to help prevent admission to hospital and consequent likely negative impact and deterioration. A wide range of community-based provision, both dementia-specific and universal, offering person-centred activities in people's own communities that includes a range of services to support carers (including respite) could provide valuable information sources and peer support.

The need to improve dementia awareness and training for everyone, particularly health and care professionals, is well recognised (ADI, 2022; Beardon et al., 2018). Training programmes

for hospital staff can produce significant improvements in their knowledge and confidence to recognise, assess and manage dementia (Galvin et al., 2010). This study's findings suggest that primary care, secondary care and social care should consider funding continuous awareness raising and training for all staff and practitioners, with a champion within each organisation.

Carers perceive that a general ward environment is unsuitable for patients living with dementia, particularly when managing their distress and confusion (Beardon et al., 2018). Making changes to the physical and psychosocial care environments in wards could improve outcomes for patients living with dementia, but Innes et al (2016) highlighted the need for staff to be adequately trained and supported if this is to be achieved. Dementia friendly-ward environments, providing a range of therapeutic activities and additional 1:1 support where needed would have positive benefits in maintaining patients' levels of functioning, including reducing the number of serious falls and improving the patient and family experience (Brooke & Herring (2016).

Treating patients living with dementia requires the collaboration of health professionals from multiple different specialities within multi-disciplinary teams (Hermann et al., 2015). Participants in this study highlighted that the use of integrated teams, or at least co-located and multi-disciplinary working practices, supports effective care for people living with dementia and helps health and care organisations to address some of the challenges identified. However, the lack of joined up IT systems and processes across health, social care and the voluntary sector is a significant barrier.

As far back as 2005, the Royal College of Psychiatrists recommended the introduction of liaison mental health services for older people within acute hospital trusts, with commissioners of health and social care working together with mental health services to improve outcomes for patients living with dementia in hospitals. Having specialist dementia advice available 24/7 to all health professionals at each stage of the pathway has produced benefits for the areas involved in this study. This should include supporting care homes to advise and train residential staff,

especially in managing people with complex needs, as well as building up a good working relationship to act as trusted assessors. Developing dementia specific support for care home staff is especially important as an estimated 70% of care home residents have dementia or severe memory problems (Alzheimer's Society, 2023).

Several participants in this study highlighted that access to assistive technology and digital solutions would help people to receive care in their home and remain there for longer. Lorenz et al (2019) found a range of technologies available, but everyday technologies were often re-purposed to meet the needs of people living with dementia or their carers (Lorenz et al., 2019).

Professionals interviewed during this study suggested that discharge planning should commence at the point of admission, with care brokers facilitating access to specialist care packages or placements, to reduce delays in hospital discharge that are likely to be longer for those living with dementia, especially if they also have distressed behaviours and/or complex needs. Access to dementia-aware domiciliary care is needed since an estimated 60% of people who receive homecare support live with dementia (Alzheimer's Society, 2023). The system needs enough intermediate care and respite provision for people living with dementia and distressed behaviours/complex needs, a suggestion consistent with the wide range of studies identified by Chenoweth et al. (2015) that raised concerns about the quality of care for people living with dementia during the hospital discharge process and while they are in transitional care.

Many participants in the study suggested that rapid response services to provide short term personal and/or nursing care in people's homes, or general support to carers, would help both prevent unnecessary hospital admissions and facilitate swift discharges. This could include assessment units in hospitals and intermediate care or transitional beds with the provision of specialist dementia support and advice. The NHS has since rolled out nationally Urgent Community Response teams providing urgent care to older people and adults with complex health needs in their homes to help avoid hospital admissions (NHS, 2020). Although these

teams are not specifically for people living with dementia, they should still benefit from the support provided that the needs of people living with dementia are recognised.

Limitations

A potential weakness of this study is the small number of locations sampled. Many health and care professionals will have an interest in supporting people living with dementia and their families and this study cannot claim to cover a full range of experiences as most interviewees were in middle or senior positions. Further research would benefit from the inclusion of professionals of varying levels of seniority to capture a wider range of views. Including the voice of people living with dementia themselves, as well as more carers and other family members, would also provide further detail based on lived experience.

Conclusion

This study was a unique investigation into how different local authority areas provide services for patients living with dementia. It found differences in working practices across areas as well as several gaps in service provision and therefore has important implications for the delivery of dementia care both locally and nationally.

Implications for practice

- Providing specialist dementia support and expertise to care homes and their staff, could help to maintain people living with dementia within their care home settings and keep them out of acute hospitals.
- Early intervention, rapid response, or intensive support teams also offer a way to provide care or support for people to avoid admission/readmission to hospital or a care home, particularly when they are a dementia specific intensive service.

- General wards would benefit from having specialist support for staff or additional support for patients living with dementia.
- Supporting the completion of ‘This is Me’ type documents would be beneficial, as would involving families in decision making and supporting carers.
- Having a dementia specialist working with or within the hospital discharge teams and multi-disciplinary working are key to making the discharge planning process effective, as are care home liaison teams, care brokerage and access to intermediate care beds or assessment beds, especially for patients with distressed behaviours or complex needs.

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