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

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Background

Admission to hospital can be harmful and distressing for people with dementia, so it is important to investigate and improve acute care provision for this patient group.

Aim

To gain a better understanding of how to meet the needs of patients with dementia during episodes of acute care, and to identify areas of effective practice across England.

Method

Qualitative interviews were undertaken with 42 professionals in five areas of England and opinions were gathered from a focus group of seven carers of people with dementia.

Findings

Working practices to support patients with dementia and their carers vary significantly by geographical area. Many examples of effective practice were identified in terms of preventing hospital admission and improving care during hospital stays, admission and discharge from hospital, and post-discharge provision.

Conclusion

Variations in 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 care provision. However, the examples of effective practice that were identified in this study could be incorporated into services to enhance the care of these patients.

Keywords

admission, best practice, clinical, dementia, discharge, neurology, patient experience, patients, practice development, professional, professional issues, research

Why you should read this article:

● To recognise the adverse effects associated with hospital admission for people with dementia
● To understand the challenges in relation to caring for people with dementia in acute services
● To consider aspects of effective practice that could be incorporated into health and social care services

Abstract

Background Admission to hospital can be harmful and distressing for people with dementia, so it is important to investigate and improve acute care provision for this patient group.

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Conclusion Variations in 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 care provision. However, the examples of effective practice that were identified in this study could be incorporated into services to enhance the care of these patients.
General wards would have patients with dementia and one fifth of the admissions are for preventative conditions (Alzheimer’s Society 2009, National Institute for Health and Care Excellence (NICE) 2024). People with dementia are admitted to hospital more frequently than those without dementia (Wolf et al 2018, Shepherd et al 2019) and the rate of readmission to hospital is higher among those with dementia (Pickens et al 2017). This patient group also has higher hospital mortality rates and longer hospital stays than patients who do not have dementia (Fogg et al 2018) and often experiences delays when being discharged from hospital (NICE 2024).

Admission to hospital can be harmful and distressing for people with dementia and they commonly experience functional decline during their admission (Dewing and 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 and Dijk 2016). Carers of people with dementia may regard changes and deterioration in the person’s condition as being due to care received during their admission, specifically negative outcomes resulting from what staff did or failed to do (Dewing and Dijk 2016). Rao et al (2016) found that following discharge from hospital, people with dementia are vulnerable and prone to further complications as they recover more slowly from illness, experience loss of mobility and may be admitted to nursing homes.

This article reports on the primary qualitative phase of this study that was undertaken as part of a wider project investigating the effect of providing care to patients with dementia in NHS acute services in England.

**Aim**

To gain a better understanding of how to meet the needs of patients with dementia during episodes of acute care, and to identify areas of effective practice across England.

**Method**

The qualitative phase of this study explored the working practices of five areas that were performing well, based on hospital episode statistics data. Areas were selected to provide a range of urban, rural and mixed geographical locations across England. Areas 1 and 5 covered an urban area, Areas 3 and 4 covered mainly rural areas with some large towns and Area 2 covered an almost entirely rural area.

The relevant dementia clinical networks were contacted to obtain introductions to clinical leads and commissioners in each area. The researchers then recruited professionals in each locality through direct email requests and snowballing (where the initial contact introduced the researchers to other professionals in the area). The selection of potential participants was based on their involvement in running or developing services and support for people with dementia. The researchers also sent emails or letters to all members of an existing ‘sounding board’ of carers of people with dementia, inviting them to take part in a focus group.

Face-to-face interviews with 42 professionals from the five selected areas were conducted, including representatives from local authorities, clinicians and NHS commissioners. The focus group comprised seven carers, all of whom were the partners or children of people with dementia. The interviews and focus group were held between May and August 2019.

**Data analysis**

The interviews and focus group discussion were recorded, transcribed and analysed using thematic analysis (Braun and Clarke 2006) by the interviewer (VB) in collaboration with the principal investigator (MK). After familiarisation with the transcripts, a thematic coding framework was developed that broadly followed the interview guide. Interview data were allocated to each part of the care pathway – prevention of admission, admission, stay, discharge, post-discharge provision – then coded under three broad themes:

- Issues and challenges identified.
- Current practices that exemplify effective practice in the interviewees’ areas.
- Effective practice planned and known about in other areas.

**Implications for practice**

- Providing specialist dementia support and expertise to care homes and their staff could help people with dementia to remain out of acute hospitals.
- Early intervention, rapid response and intensive support teams offer a way to provide care or support for people to avoid admission or readmission to hospital or a care home, particularly when they are dementia-specific.
- General wards would benefit from having specialist support for staff or additional support for patients with dementia.
- Supporting the completion of ‘This is Me’ or similar documents would be beneficial, as would involving families in decision-making and supporting carers.
- Having a dementia specialist working with or in the hospital discharge teams and multidisciplinary working are important to making the discharge planning process effective, as are care home liaison teams, care brokerage and access to intermediate care beds or assessment beds.
all professionals employed by an NHS trust, before they were invited to take part in an interview. A participant information sheet was provided to all participants and written consent was obtained before the start of the interviews or focus group. The data were anonymised to protect participants’ confidentiality.

Findings
Findings from the interviews and focus group are presented under five points on the patient pathway:

- Prevention of admission to hospital.
- Admission to hospital.
- Hospital stays.
- Discharge from hospital.
- Post-discharge provision.

Several systemic challenges identified by the participants are also outlined.

Prevention of admission to hospital
There appeared to be some degree of variation in the preventive support and healthcare services accessed by people according to their level of affluence and whether they were in rural or urban 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 in their county and/or neighbouring counties led to inconsistency in provision and access to services. Participants from the two urban areas highlighted issues for people from 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. There were also gaps in dementia-specific respite care, support for carers and out-of-hours crisis support.

Several areas had Admiral Nurses (specialist nurses provided by Dementia UK) 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 in the community and had moved away from day centre provision to more enabling community-based provision.

Participants mentioned devices, digital care and assistive technology solutions that could be provided to enable people with dementia to live safely at home for longer. These included: geo-locator devices; sensors that detect patterns of movement; alarmed carousels for medicines; memo minders or pager-like reminders; pressure mats in front of doors; pressure sensors on beds where changes trigger an alert; and responder services to call alarms or alerts.

The 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. Four areas had an intensive support team for all patients, which aimed to avoid admissions or readmissions 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 to rapidly discharge people from the units. Two hospitals had a ‘virtual ward’ that was run by community matrons to avoid admissions, while two areas had an intermediate care service that was used to prevent hospital admissions and manage discharges. However, only three of the areas had these types of intensive services that were specific to people with dementia.

Admission to hospital
One issue faced by some areas was the national shortage of mental health acute beds, especially for patients in crisis. Another issue was a lack of information about each patient. Several hospitals acknowledged that they did not have effective screening for delirium or dementia, although two hospitals highlighted the use of a cognitive screening tool or frailty assessment. Area 5 was aiming for earlier assessments and identification of people with dementia in the emergency department (ED).

NHS risk management policies meant that hospital staff tended to take ‘the safer route’ by admitting patients who presented at the ED with certain symptoms if they also had dementia, whereas they would not admit patients with the same symptoms who did not have dementia.

Most of the areas had specialist wards in 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 by building connections with the referring mental health workers and encouraging them to explore other options. Some acute hospitals had wards specifically for patients with dementia. When one hospital had to use general wards for patients with dementia and distressed behaviours, they tried to put extra provision in place such as one-to-one staffing for the hospital stay.

Many areas mentioned the ‘This is Me’ document or an equivalent, as well as talking to family members to obtain information about people with dementia. This is Me is a simple leaflet for anyone receiving professional care who has 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. One hospital had a shorter pictorial version of this. However, many patients did not have this type of document completed before their admission.

Many areas used the ‘red bag’ scheme – where a bag containing important paperwork, medicines and personal items is handed to ambulance crews by carers or care home staff to accompany care home residents into hospital. However, bags were often not returned to care homes afterwards and awareness of their purpose typically declined over time.

Hospital stays

Participants identified that the main issue for people with dementia staying in hospital was the ward environment, which was 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)

Some effective practice was identified in relation to making the ward environment dementia friendly, for example in terms of signage, colour of décor and providing access to outside areas, and using ways to identify patients with dementia such as a forget-me-not flower symbol to show that someone is experiencing memory problems. A range of meaningful activities were also provided for patients – such as reminiscence work, music and art – to keep them engaged and active.

In several areas, the support provided by dementia specialist practitioners to professionals on the hospital wards and in the ED was seen as valuable. Specialist advice and expertise was shared by various professional groups, including specialist dementia practitioner trainers, mental health liaison services and lead nurses or staff based on the ward who had managed a high proportion of patients with dementia.

Support for carers was considered important, with several hospitals using carers’ passports. Some hospitals had signed up to John’s Campaign, which calls for a policy of welcoming family carers onto wards outside of normal visiting times according to the needs of the person with dementia, 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, and one hospital provided support specifically for carers. One carer emphasised the importance of carer involvement, stating:

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

Discharge from hospital

Interviewees from all the areas stated that discharge planning for all patients started almost at the point of admission, or as early as possible. Most areas had robust delayed transfer of care processes for all patients, but reported that patients with dementia – especially those with complex issues – were likely to have a relatively high number of delayed transfer of care days.

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

Interviewees in Areas 1 and 5 were positive about the care brokerage teams based in their local hospitals and funded by social care, which were for all patients – not just those with dementia.

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 highly positive about the ‘discharge to assess’ model, which supports patients who are clinically stable but need further assessment of their ongoing health and social care needs to leave hospital. However, there were barriers to following this pathway for people with dementia and one area reported that few of these patients used it.

Several areas emphasised the importance of developing effective relationships and trust with care homes, which was key to ensuring the smooth discharge of patients there. Some areas had care home liaison teams that also acted as trusted assessors, a scheme which aims 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. This role was highly valued because it expedited discharges.

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

**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 positive outcomes for patients discharged there, but there were too few intermediate care beds available.

Several areas highlighted that they did not have a robust pathway for discharging patients with delirium and/or dementia and it was identified that delays in arranging care packages or carrying out assessments, including by care homes, could delay discharges. For example, one interviewee stated:

‘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, while another area 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 for patients due to the long travel times needed for carers to visit them. One area stated that reablement and/or physiotherapy were highly 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.’

(Interviewee in Area 2)

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 care packages to be authorised. This had either reduced the length of hospital stay or reduced delayed transfers of care. Additionally, some areas had a form of step-down support in the community after discharge for all patients. Several areas used the voluntary sector to provide support to any patient who needed only a small amount of support to return home. However, people with dementia were less likely than others to receive these types of services.

Most areas had intermediate care or transitional beds in 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 multidisciplinary team. Interviewees in Area 4 said that few patients were discharged into intermediate care beds since their observation bay in the ED could start to reverse an acute episode within 24-48 hours and because their community services successfully returned patients to where they were living previously. Area 1 paid a dementia premium to support care homes to manage people with dementia, while Area 5 had upskilled care homes to be able to receive them back more quickly.

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

The general pressures facing care provision exacerbated the difficulties in keeping people with dementia out of hospital or discharging them quickly. Such pressures included: inconsistency in the practices of care agencies; variability in the quality of care; some care agencies no longer accepting social care rates paid by local authorities; workforce issues for care and nursing homes in terms of staff recruitment and retention; and lack of respite provision.
Systemic challenges
Awareness of dementia appeared to be variable across different professional groups and organisations. Raising awareness needed to be a continuous process and embedded across services to avoid a decrease in awareness if an important member of staff left, such as a dementia champion. Most hospital staff had received at least a basic level of dementia training in their induction, but the levels of awareness among GPs was variable and they were not always aware of next steps or confident about supporting someone 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, and this was reflected by some of the professionals interviewed.

All the areas identified multidisciplinary and integrated working as being essential to improving outcomes. Several participants felt that while there could be tensions between health and social care services regarding budgets, front-line staff worked well together, especially where there were joint and multidisciplinary approaches. Most areas had a dementia forum or reference group in place, which was effective in bringing different professional groups together:

‘Those key players [from different organisations and disciplines] 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 for health and social care as an issue, with the added pressure on resources caused by the increasing demand on services due to the growing number of people with dementia.

All the areas mentioned issues with information technology (IT) systems and data sharing between different health and social care organisations. Health and social care staff used separate systems for case management, so there was often duplicated data inputting and the need to contact other organisations to clarify information or check on previous interventions and care.

Area 4 was piloting a population health management intelligence system that used data to proactively identify people before they reached a crisis. This system records data from different sources, converting it into datasets with different levels of access. Interviewees in this area believed that this could potentially have a transformational effect.

Discussion
It is crucial to implement a dignified, person-centred approach to the acute care of patients with dementia that focuses on the unique situation of each individual (Beardon et al 2018, Alzheimer’s Disease International 2022). While this is the ideal, Røsvik and Rokstad (2020) acknowledged there was a need to improve hospital staff’s competence in person-centred care and managing this patient group. Participants in the present study advocated treating people with dementia in a holistic, person-centred way and ensuring that processes involved families and carers.

Supporting families and friends who have a caring role is important because people with dementia, their carers and healthcare professionals form an important triad within a care relationship that requires equilibrium to thrive (Alzheimer’s Disease International 2022). This study highlighted the variable support available for people with dementia and their carers, including support to help prevent admission to hospital and the likely negative effects and deterioration associated with admission. A wide range of community-based provision – both dementia-specific and universal – offering person-centred activities and services to people with dementia and their carers could provide valuable sources of information and peer support.

The need to improve dementia awareness and training for everyone, particularly health and care professionals, is well recognised (Beardon et al 2018, Alzheimer’s Disease International 2022). 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 dementia champion in each organisation.

Many carers perceive that a general ward environment is unsuitable for patients 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 these patients, but Innes et al (2016) emphasised the need for staff to be adequately trained and supported if this is to be achieved. Dementia-friendly ward environments that provide a range of...
Therapeutic activities and additional one-to-one support where necessary could have benefits in terms of maintaining patients’ levels of functioning, including reducing the number of serious falls and improving the patient and family experience of care (Brooke and Herring 2016).

Treating patients with dementia requires collaboration between healthcare professionals from various specialties working in multidisciplinary teams (Hermann et al 2015). Participants in this study highlighted that the use of integrated teams, or at least co-located and multidisciplinary working practices, supports effective care for people with dementia and helps health and social 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 mental health liaison services for older people in acute hospital trusts, with health and social care commissioners working together with mental health services to improve outcomes for patients with dementia in hospitals. Having specialist dementia advice available 24/7 to all healthcare 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 an effective working relationship to act as trusted assessors. Developing dementia-specific support for care home staff is especially important since an estimated 70% of care home residents have dementia or severe memory problems (Alzheimer’s Society 2024b).

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 that everyday technologies, such as baby monitors, pendant alarms and medication reminders, were often repurposed to meet the needs of people with dementia and/or their carers.

The professionals interviewed during this study suggested that discharge planning should start 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 with dementia, especially if they also have distressed behaviours and/or complex needs. Access to dementia-aware domiciliary care is necessary since an estimated 60% of people who receive homecare support have dementia (Alzheimer’s Society 2024b). The system needs sufficient intermediate care and respite provision for people with dementia and distressed behaviours and/or 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 with dementia during the hospital discharge process and while they are in transitional care.

Many participants in this 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 to 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. NHS England (2020) has since extended urgent community response teams nationally to provide urgent care to older people and adults with complex health needs in their homes, thereby helping to avoid hospital admissions. Although these teams are not specifically for people with dementia, they should still benefit from the support provided, as long as their needs are recognised.

Limitations

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

Conclusion

This study investigated how different local authority areas provide services for patients with dementia. It found variations in working practices across these different areas, as well as several gaps in service provision and examples of effective practice. Therefore, the findings of this study have important implications for the delivery of dementia care locally and nationally.


Resvik L, Rakstad AM (2020) What are the needs of people with dementia in acute hospital settings, and what interventions are made to meet these needs? A systematic integrative review of the literature. BMC Health Services Research. 20, 1, 723. doi: 10.1186/s12913-020-05868-3


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