Impact of the COVID-19 pandemic on hospital care for people with dementia: Feedback from carers/families and hospital leads for dementia.

- *Front cover image: Carol Fordyce*

Email address: nad@rcpsych.ac.uk

Website: www.rcpsych.ac.uk

Overview

The National Audit of Dementia (NAD) is a clinical audit programme commissioned by the Healthcare Quality Improvement Partnership on behalf of NHS England and the Welsh Government looking at quality of care received by people with dementia in general hospitals.

At the start of the COVID-19 pandemic, acute general hospitals had to rapidly respond to increased demand for critical care. In the face of this unprecedented crisis, non-urgent care was suspended, staff were redeployed, and audits and quality improvement programmes were put on hold.

Following consultation with stakeholders the NAD team developed a plan to examine how the pandemic had affected inpatient care for people with dementia and to identify examples of good practice. We developed three separate short surveys for people with dementia, their carers/families and for hospital leads for dementia. The surveys were open between 17 June and 17 July 2020. Completion was optional and all feedback anonymous. Links were emailed directly to clinicians leading their organisation's dementia strategy (hospital leads), and surveys for people with dementia and their carers were circulated online, via social media and through networks of representative organisations and charities.

The results of the surveys highlight the negative impact of the pandemic on the quality of inpatient care for people with dementia, as well as providing encouraging examples of emerging good practice. We present an initial breakdown of the results below.

We hope that sharing these findings in a timely manner will assist hospitals in their efforts to meet the needs of people with dementia admitted to hospital in these challenging times.

Participation

- 57 responses were received from hospital leads, 53 from England and four from Wales. This represents 25-30% of acute general hospitals in these countries.
- 32 responses were received from carers for people with dementia, from 21 hospitals across England.
- 13 responses were received from people with dementia, from a single hospital, and included only two comments, both generally favourable about staff.

A full breakdown is available on our website.

Key themes and findings

Online appendices:

- Overall results breakdown and comment theme count, hospital leads survey
- Overall results breakdown and comment theme count, carer survey
- Overall results breakdown from people with dementia
- Acknowledgements (participants in consultations about the survey

This interim report includes feedback showing different approaches and experiences across different hospitals (feedback from people with dementia from a single hospital is included in the appendices). Due to the short data collection period and sample sizes it should not be read as representative of activity/experiences in all hospitals.

Care in hospitals pre-lockdown

People with dementia are often negatively affected by an admission to hospital. Dementia can affect the ability to communicate care needs, pain or distress and this is often made worse by ill health and unfamiliar surroundings. Previously, the majority of hospitals in England and Wales had adopted strategies/implementation plans aimed at addressing the specific care needs and support required by people with dementia (see National Audit of Dementia 2019 report). Strategic planning addresses the need for effective leadership and integrated care planning to provide person-centred care. It covers all aspects of the patient journey from admission to discharge, including:

- Comprehensive assessment of physical and mental health and social circumstances
- Carer involvement: ensuring that carers/family of people living with dementia are consistently involved in plans and updated about care. Schemes in place to support this include flexible visiting policies which allow carers to remain with the patient to provide advocacy and support (see John's Campaign).
- Communication: sharing information appropriately about a person's care needs and preferences.
- Staffing and training: sufficient staff skilled in identifying and addressing the physical, psychological and social needs of people with dementia.
- Environment and activities: many hospitals had reviewed their physical environment and adapted areas or wards to be 'dementia friendly'. These included the introduction of activities and shared mealtimes aimed at increasing social interaction.
- Discharge planning: to ensure safe and effective discharge from hospital for people with dementia taking into account the person's needs and circumstances.

Impact on organisational strategy

28 (49%) hospital leads said that dementia strategy, planning and/or projects were suspended.

> *…it was a difficult time for all and the Dementia focus of the medical teams was taken away… We have made adjustments on the ward so that our Dementia programme can resume… We had just finalised the new five year strategy so we are now in the process of reviewing it to ensure that we are incorporating any government/local guidance around COVID-19.* (Hospital lead)

15 (26%) leads reported that strategies have been updated or created because of the pandemic. Seven (12%) felt that there is a now a better awareness of dementia and more engagement from Trust/health board members or senior management.

> *The impact of Covid-19 has been to highlight the particular needs of patients with delirium and dementia in terms of safe in-patient care and rapid discharge. We feel that this may mean that the senior management team at the Trust are more invested and engaged with the new dementia strategy which was being developed just prior to the onset of the pandemic. (Hospital lead)*

Visiting the person with dementia, communication and family/carer involvement

From mid-March, all visiting in hospitals was suspended with very few exceptions. In April, NHS England clarified that people with dementia experiencing distress could be visited by one key person.

Feedback from hospital leads and carers about visiting

We asked hospital leads and carers about how visiting guidance had been implemented and explained.

One hospital lead said that carers had not been allowed to visit at all, and 15 (26%) that visiting had only been allowed at end of life. 19 (33%) stated that it had been allowed on a limited basis in various ways: with appropriate PPE, assessing need on an individual basis, allowing one person to visit the patient, or by appointment. Five (9%), commented that communication via other means such as video calls had been encouraged, instead of visiting.

> *Patients are distressed that they are unable to see relatives, and often don't understand or remember why they feel abandoned* (Hospital lead)

15 comments from hospital leads spoke of the difficulties experienced by people with dementia due to visiting restrictions, including isolation, loneliness and lack of stimulation.

> *they were uncaring of [relative's] mental wellbeing, she is frightened. While I was with her she was calm* (Carer)

27 (90%) carers said that they had not been allowed to visit the person they cared for during their admission. 13 (43%) carers had been given no explanation about visiting procedures. Five carer comments referred to the negative impact reduced visiting had had on the person with dementia.

Where direct contact with carers is so limited, other means of communication and carer involvement are of heightened importance. Communication with carers helps provide reassurance to the person with dementia and gives staff necessary information about the person's needs, including how dementia affects them.

> *Was told [staying with relative] was fine. Got there and was told it was not fine. The guy there made a right song and dance about it* (Carer)

Feedback from hospital leads and carers about communication

> *Plenty of information from a special team that the hospital set up to communicate with families* (Carer)

91 comments from hospital leads were about methods that had been introduced to maintain or improve communication with carers. This included the use of technology such as video calls or e-cards, and setting up dedicated teams to maintain telephone contact with families and collect information needed about the person with dementia.

Nine comments from carers reflected that they had been able to have contact with the person with dementia, via the use of technology or phone updates provided by staff.

> *Left a mobile phone but nobody free to help mum with it* (Carer)

Seven comments from hospital leads said that communication with family/carers was not working well.
Six carer comments said that staff could not facilitate phone calls with the person with

dementia, or that it did not work well for them.

Hospital leads also commented on communication with the person with dementia and how it had been affected by the use of PPE, with 29 comments referring to communication made more difficult and five on how staff were trying to improve communication whilst wearing PPE. Workarounds included use of laminated photographs of staff and communication tools (e.g. Cue cards).

Impact on staffing and availability of specialist support

Hospitals were reconfigured into COVID (hot) and non-COVID (cold) areas to minimise contact and optimise resources. Staff from many specialities including dementia teams were redeployed as part of the reconfiguration.

Feedback from hospital leads and carers about staffing

16 comments from hospital leads referred to reductions in numbers of staff caring for people with dementia (due to redeployment, sickness and shielding), and a further 12 mentioned that volunteer support was also reduced.

36 (63%) hospital leads reported that members of their team were redeployed from a specialist role supporting people with dementia or elderly patients. 11 (19%) leads had both their dementia lead and dementia team members redeployed.

> *Loss of care crew and staff redeployment away from dementia ward. Staff sickness covered by non-dementia trained colleagues from other departments* (Hospital lead)

Specialist support for people with dementia from dementia and delirium teams, care of elderly teams or outreach team was affected with 26% of hospital leads reporting that there was no support. 61% of hospital leads reported face to face support was available,and 46% had remote support on COVID wards. On non-COVID wards availability was reduced, 49% reported face to face support and 28% remote support.

20 comments reflect that hospital leads felt that staff redeployment had a negative impact on care provided to people with dementia, due to inexperienced staff and a lack of access to expertise in dementia/delirium. 14 comments from hospital leads and two from carers stated that staff who lacked experience were caring for people with dementia.

11 comments from leads detailed enhanced staffing, including higher staffing levels and increased 24-hour cover, giving more time for patient/staff interaction. Five comments described how input from volunteers had been used to aid communication and family liaison.

> *As the numbers of patients with dementia was reduced, particularly in the early stages of lockdown the Specialist Dementia team had more available time to support patients with dementia for longer periods as did the ward staff* (Hospital lead)

Impact on admission and discharge

Many hospitals saw a reduction in admissions of people with dementia, as the aim was to avoid admission where care could be provided elsewhere. Members of the public were aware of hospital-based infection risk and fewer people attended Accident and Emergency departments (BMJ 2020; 369:m1401)

> *We were failed to be informed of patient contracting Covid-19 only found on discharge letter a day after discharge to vulnerable shielding partner.* (Carer)

At the start of 'lockdown' procedures were introduced which meant that patients could be discharged more quickly to reduce infection risk associated with hospital admission.

Feedback from hospital leads and carers about admission and discharge

Six (11%) hospital leads said that fewer people with dementia were admitted, and four (7%) generally commented that admissions had been avoided where possible, due to availability of alternative care or increased family support at the start of 'lockdown'. Avoidance of hospital admission and its impact was thought beneficial to people with dementia by most leads. Two (4%) leads noted concern that people who required hospital care might not have attended due to fears of infection risk.

> *Less inappropriate admissions of patients with dementia as families try and support and keep at home to avoid COVID exposure…*(Hospital lead)

We asked how newly introduced rapid discharge procedures had affected people with dementia. 48 comments said that the rapid discharge process was more efficient, reducing length of stay and helping to prevent delayed transfers of care.

> *It seems to have got patients out more quickly which has been beneficial as less chance of decline both physically and mentally and of getting further infections* (Hospital lead)

23 comments expressed concern that the new procedures meant that discharge could be too fast, poorly planned or unsafe. Additionally, 27 comments from leads stated that these changes had caused an increase in length of stay and more delayed transfers of care. Seven leads noted a lack of social services staff in hospital to assist with discharge, or decreased community support.

17 (55%) carers said that they were kept informed about plans for treatment and discharge. However, comments suggested this did not always run smoothly. Carer comments also reflected problems arising where this did not happen.

19 (79%) reported that the person with dementia was able to return to the place that they were living before their admission.

> *Treatment and care plans were arranged and then we have been told what they are! At the start we stated we had LPA (Lasting Power of Attorney) but really meant little!* (Carer)

Impact on patient care
(including environment)

Ward reorganisation, staff redeployment and reduction in activities has inevitably affected the care of people with dementia in hospital. The need to separate COVID positive patients has also led to more frequent bed moves, which has a detrimental impact on continuity of care and the orientation of people with dementia.

Feedback from hospital leads and carers about environment/ patient care

15 comments from hospital leads related to the loss of specialty/designated dementia wards, or to patients with dementia being placed on wards not suited to their needs. 13 comments said that activities aimed at improving stimulation and social engagement had been suspended. However, 12 comments were about more activities or resources for activities available.

21 hospital leads said that there had been an increase in the number of times people with

dementia had moved wards or beds. In contrast, three said they had decreased.

10 comments from leads related to negative impact on care quality, such as a lack of input from therapists whose movements around the hospital were restricted. Six commented on personal information about the patient not being recorded or used. Seven felt that care quality had been maintained despite difficulties.

16 (50%) carers said that hospital staff asked them about the needs of the person that they look after.

12 comments from carers highlighted concerns about the treatment of the person with dementia.

They had no time for her. When [relative] was moved onto the open ward, no one gave her anything to drink for 3 hours. [relative] suffers from dehydration, constipation and a UTI (Carer)

Four carers commented that the care had generally been good.

Quite rightly, their first concern was safeguarding the staff and patients. I know it is very damaging for dementia patients to be in unfamiliar situations but [relative] was cared for and looked after despite it being at the height of the outbreak (Carer)

New ways of working

Several hospital leads referred to new ways of working which have emerged in response to the challenges of the pandemic and hospital reorganisation. A summary of all of these is presented in the table below:

Emerging new practice:

- Joint working/communication between services has improved (12 comments from nine leads)

Enhanced working between mental health and eldercare apparent and use of remote and virtual meetings has improved communication, creating a more dynamic service with less impact on time.

- Teams to liaise with carers/family members introduced e.g. family support team (10 comments from nine leads)

We also had a dedicated team of people whose role was solely communicating with relatives and providing updates

- More/better communication with family/carers including use of technology e.g. tablets, video-calls, e-cards (91 comments from 46 leads)

Videocalls enable families to stay in touch and patients to see familiar faces

- Clinics/assessments/referrals/reviews being completed via phone/video call (16 comments from 13 leads) and a new team developed to manage discharge (one comment)

Follow up of delirium patients changed to phone call - we have been able to do this more rapidly, contact more patients and this has been working well

- Training methods changed e.g. virtual training, peer to peer training on wards (10 comments from eight leads)

Ward based teaching and completing reflective sessions on real life scenarios and sharing lessons learnt.