

# Understanding and improving experiences of care in hospital for people living with dementia, their carers and staff: three systematic reviews

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## Scientific summary

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# Scientific summary

## Background

Demographic ageing is associated with increased rates of acute general hospital admissions among older people with multiple comorbidities and complex care needs. Approximately 40% of patients over the age of 70 years admitted to hospital have dementia. For people living with dementia, hospitals can be overwhelming and confusing, impacting their well-being and the ability to optimise their care. In addition, what happens in hospitals can have a profound and permanent effect on individuals and their families, in terms of not only their inpatient experience, but also their ongoing health and the decisions that are made about their future. The need to improve the experience of care for people living with dementia is well recognised, but how best to do this is not known. We aimed to address this uncertainty by bringing together the evidence on experience of care and the experience and effectiveness of interventions aimed at improving it, and integrating the findings into one overarching synthesis.

## Objectives

Three linked systematic reviews and an overarching synthesis were conducted. The reviews aimed to explore the experience of care in hospital (review 1), the experience of interventions that have targeted improving the experience of care (review 2) and the effectiveness and cost-effectiveness of interventions aiming to improve the experience of care in hospital (review 3) for people living with dementia, their carers and the staff who care for them. For all three reviews, experience of care was defined as 'the extent to which a person perceives that needs arising from physical and emotional aspects of being ill are met'. The overarching synthesis aimed to integrate the findings across the reviews using both deductive and inductive approaches.

## Stakeholder involvement

The project integrated end-user involvement throughout the reviews in the form of input and feedback from public, clinical and academic topic experts, as well as consultation on preliminary findings with a range of internal and external stakeholders.

## Data sources used

Sixteen electronic databases were searched across the three reviews on 9 and 10 May 2018 with no date restrictions: MEDLINE, EMBASE, PsycINFO, Health Management Information Consortium and Social Policy & Practice (via OvidSp), Cochrane Database of Systematic Reviews and Cochrane Central Register of Controlled Trials (via the Cochrane Library), Cumulative Index to Nursing and Allied Health Literature (via EBSCOhost), British Nursing Index and Applied Social Sciences Index and Abstracts (via ProQuest), NHS Economic Evaluation Database, Health Technology Assessment Database and Database of Abstracts of Reviews of Effects (via the Centre for Reviews and Dissemination), Social Sciences Citation Index and Conference Proceedings Citation Index (via Web of Science) and ProQuest Dissertation and Theses Global. Forwards and backwards citation chasing, searches for sibling articles, author contact and grey literature searches were also undertaken.

## Summaries of reviews 1 and 2

### Methods

Two independent reviewers were involved in study selection, data extraction and quality appraisal. Inclusion criteria were qualitative articles focusing on the experience of care or improving the experience of care for older adults with dementia in the hospital setting. Studies that focused on older adults with delirium or acute confusion, or that explored clinical aspects of dementia (e.g. prevalence, assessment, diagnosis), were excluded. Screening at both title and abstract and full-text stage was carried out by two researchers independently, referring to a third reviewer where necessary. Two reviewers independently conducted quality appraisal in parallel with data extraction.

Owing to the large number of papers that met the inclusion criteria for review 1, prioritisation of the included studies was conducted. Papers were evaluated by two reviewers independently on scales of data richness, methodological quality and conceptual contribution. Findings from the highest-priority papers contributed to the synthesis, and medium-priority studies were checked for support or refutation of findings.

Data analysis and synthesis followed the approach of meta-ethnography. Subreviews translating findings about experiences from reviews 1 and 2 for people living with dementia (subreview A), carers (subreview B) and staff (subreview C) were conducted. Because of the conceptual strength of the review 1 prioritised papers, the subreviews were synthesised in a 'line of argument' in which the translations and refutations of concepts identified across prioritised studies were combined to provide an overall narrative.

### Findings

In review 1, 63 studies were reported in 82 papers. Twenty-four studies reported the experiences of hospital staff, students and/or volunteers only, 14 studies reported the experiences of carers only, and two studies reported the experiences of people living with dementia only. Twenty-two studies reported the experiences of mixed types of participants. Studies were conducted in 15 countries, with 28 out of the 63 studies conducted in the UK.

In review 2, 14 studies were reported in 16 papers. Seven studies reported the experiences of hospital staff, students and/or volunteers only and seven studies reported the experiences of mixed types of participants. Studies were conducted in six countries, with 9 out of the 14 studies conducted in the UK. Interventions were placed into one of six categories according to their focus: 'improving staff information, knowledge and skills' ( $n = 5$ ), 'increasing ward capacity' ( $n = 2$ ), 'activity-based interventions for people living with dementia' ( $n = 2$ ), 'changes to ward environment' ( $n = 2$ ), 'support for carers' ( $n = 2$ ) and 'special care units' ( $n = 1$ ).

Among people living with dementia, the main theme was 'feeling afraid and insecure'. Care orientated around supporting personhood was found to be crucial because it acted to decrease the disorientation people living with dementia faced in the unfamiliar environment of the hospital, which could result in intense fear and insecurity. People living with dementia communicated this distress through behaviours that disrupted hospital routines and care. Factors that were found to reduce fear and insecurity included training staff, volunteers and/or carers to seek unmet need, centring approaches on learning the individual likes and dislikes of people living with dementia, providing occupation, and respecting the dignity and personhood of people living with dementia. Such approaches worked to reduce distressed behaviours. Among staff, the main theme was 'feeling prevented from providing good care'. Staff felt that a person-centred approach is needed for the delivery of optimal care, as it helps alleviate psychological distress for people living with dementia, freeing staff to provide physical care, and represents closely the values staff describe that relate to good care. When staff felt prevented from providing such care, they experienced moral distress and reduced job satisfaction. Barriers to providing person-centred care included lack of knowledge about care for people living with dementia, and

institutional and ward cultures that prioritised task-/routine-focused care. Interventions supported the feasibility of providing person-centred care by showing that staff felt more confident through training, and could be freed to focus on physical tasks and routine by the addition of capacity in the form of volunteers, students and carers who interacted personally with people living with dementia, and through access technology. Among carers, the main theme was 'feeling stressed and desiring inclusion'. Carers expected both the physical and the psychological needs of people living with dementia to be met, and that staff would consult them about the personal preferences and home caring routines of people living with dementia, as well as share information with them about the ongoing health of people living with dementia. However, this did not always occur. When staff acknowledged the value of carers' personal knowledge of how to care for people living with dementia and carers' unique ability to provide emotional support, this resulted in positive carer experiences, as well as improved care for people living with dementia.

The line of argument across the reviews was that *a change of hospital culture is needed before person-centred care can become routine*. The more staff were supported to deliver person-centred care for people living with dementia, the better the experience of care for everyone. However, unless hospital cultures that prioritise task-/routine-focused care change to ones that prioritise psychological and physical care, this cannot happen. The aspects of hospital cultures that need to change to allow person-centred care include workforce capacity; training and ward priorities around meeting the unmet needs of people living with dementia; physical environments that support familiarisation and have space for social interaction and activities; inclusive approaches to carers; and cultures of sharing knowledge and information between peers, and across hierarchies and roles.

## Summary of review 3

### Methods

Two independent reviewers were involved in study selection, data extraction and quality appraisal. The inclusion criteria specified quantitative study designs reporting comparative data or economic evaluations of any intervention delivered to people living with dementia and their carers aiming to improve their experience of care in hospital. Studies including older adults with delirium/confusion or other physical or mental health conditions were included if data for people living with dementia were retrievable and represented  $\geq 50\%$  of the sample. Interventions delivered to hospital staff were included if outcomes were reported relating to the experience of caring for people living with dementia and/or their carers. For the assessment of cost-effectiveness, economic evaluations and comparative cost studies of interventions meeting the inclusion criteria (whether a randomised controlled trial, an observational study, a cost-outcome analysis or an economic evaluation) were included. Two reviewers independently conducted quality appraisal in parallel with data extraction.

Findings were tabulated using sample sizes, means and standard deviations for continuous outcomes, and frequencies and percentages for categorical outcomes. Effectiveness was assessed based on the differences in means between intervention and control groups at post-test or between pre- and post-intervention measurements, depending on study design. Effect sizes for continuous outcomes were calculated to assess differences and aid the interpretation of findings using standardised mean differences.

### Findings

Twenty-five studies reported in 26 papers met the inclusion criteria and were included in the synthesis: three randomised controlled trials, one cluster randomised controlled trial, four controlled before-and-after studies, 13 uncontrolled before-and-after studies, two time series studies and two prospective cohort studies. These studies reported on five main categories of intervention: 'improving staff information, knowledge and skills' ( $n = 12$ ), 'activity-based interventions for people living with dementia' ( $n = 6$ ), 'special care units' ( $n = 4$ ), 'increasing ward capacity' ( $n = 1$ ) and 'support for carers'

( $n = 1$ ). Fifteen studies reported outcomes for hospital staff, 14 studies reported outcomes for people living with dementia and five studies reported outcomes for carers. Study duration varied across studies but was generally short and ranged from 9 days to 24 months.

There is limited and poor-quality evidence to support the effectiveness of interventions to improve the experience of care for people living with dementia or their carers in hospital. The most studied interventions, activity-based interventions, evaluated in six studies, indicated positive trends regarding their effectiveness on the engagement, mood and behaviour of people living with dementia, although the sample sizes were small and the quality of studies was low. Evidence of beneficial effects on aspects of well-being of people living with dementia or on satisfaction and well-being of carers relied on few studies of varying methodological quality. Among studies on staff, confidence in providing dementia care was the most studied outcome. Five out of nine studies found statistically significant increases in staff confidence following training to better care for people living with dementia. There was very limited evidence to support intervention effectiveness in terms of improved attitudes towards people living with dementia, confidence with dementia communication or communication among staff, satisfaction in caring and medication use. Staff well-being, including stress, absences and job satisfaction, was assessed in individual studies of interventions to increase ward capacity, activity interventions or special care units without significant changes reported. Despite the number of studies evaluating the impact on hospital staff, the evidence is not sufficient to evaluate intervention effectiveness on the range of outcomes reported in the included studies. The literature on the cost-effectiveness of interventions is sparse, with only four studies identified, and the results reported in these studies are uncertain and difficult to compare.

## **Overarching synthesis and development of co-produced pointers for service change**

### **Methods**

We drew from the review 1 line of argument to organise findings from reviews 2 and 3 in the overarching synthesis. Problematic aspects of experiences of care identified in review 1 were used to organise findings from reviews 2 and 3 about what interventions did to attempt to improve experiences of care, how people perceived such changes, and how well the interventions worked/how cost-effective they were.

### **Findings**

Increased recognition for care for dementia through investment in training and workforce capacities is a key factor for transforming ward cultures that currently do not value care for dementia. Such changes are likely to improve the job satisfaction and well-being of staff who want to provide good care to people living with dementia but feel helpless to do so in the face of acute ward cultures that prioritise task-/routine-focused care, and to result in a better experience of care for people living with dementia and carers alike. Although an inclusive approach to carers, support for an environment that fosters familiarisation and a culture that promotes information sharing are perceived as key requirements for delivering person-centred care, the evidence for how to do this is lacking.

### **Co-production of DEMENTIA CARE pointers for service change**

The findings from the three reviews and overarching synthesis were shared with the Project Advisory Group and with wider external stakeholders. Through discussion and iteration, key areas for future consideration were agreed and developed into 'pointers for service change'. The DEMENTIA CARE pointers for service change highlight institutional and environment practices and processes that warrant consideration when thinking about how to improve the experiences of care for people living with dementia in hospital. The pointers cover the areas of dementia understanding, education and training; modelling person-centred care from leadership; the environment; not being alone; time; information-sharing; access to resources; communication; ask family; raise the profile of dementia care; and engaging volunteers.

### **Discussion and implications for practice and research**

The routine delivery of person-centred care for people living with dementia will not happen until hospital cultures that currently prioritise task-/routine-focused care change to cultures that prioritise both psychological and physical care. There is some evidence supporting a positive impact of dementia care units and activity-based or tailored interventions on the experiences of care for people living with dementia, but the research in this area is still quite limited. The findings from our reviews suggest that focusing on the DEMENTIA CARE pointers for service change could help improve experience of care. However, how to implement such changes in organisational and ward cultures and how to evidence the benefit of a hospital-wide person-centred care approach for people living with dementia remain to be established.

### **Conclusion**

Evidence suggests that although people living with dementia can have a good experience of care in hospital, for many this is still not happening. When staff cannot provide the care for people living with dementia that they would like to give, this has a negative effect on people living with dementia, their carers and the staff themselves. To improve the experience of care in hospital for people living with dementia, there needs to be a transformation of organisational and ward cultures that recognise and value the status of dementia care. Although increases to workforce capacity, physical environments that support familiarisation, social interaction and activities, inclusive carer policies and cultures of sharing knowledge have shown promise in this area, further research needs to identify how best to do this, and how to maintain the changes in the long term.

### **Study registration**

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