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Supporting general hospital staff to provide dementia sensitive care. A realist evaluation.

Abstract

Background: There are an increasing number of interventions to improve hospital care for patients with dementia. Evidence for their impact on staff actions and patient outcomes is, however, limited and context dependent.

Objective: To explain the factors that support hospital staff to provide dementia sensitive care and with what outcomes for patients with dementia.

Design: A realist evaluation using a two-site case study approach.

Setting: Two hospital trusts in the East of England. Site 1 had a ward for patients with dementia that would address their medical and mental health needs. Site 2 used a team of healthcare assistants, who had support from dementia specialist nurses, to work with patients with dementia across the hospital.

Participants: Hospital staff who had a responsibility for inpatients with dementia (healthcare assistants, nurses, medical staff, allied healthcare professionals and support staff) (n=36), patients with dementia (n=28), and family carers of patients with dementia (n=2).

Methods: A three stage realist evaluation: 1) building the programme theory of what works and when; 2) testing the programme theory through empirical data (80 hours non-participant observation, 42 interviews, 28 patient medical notes, 27 neuropsychiatric inventory, and documentary review); 3) synthesis and verification of findings with key stakeholders.

Findings: The programme theory comprised six interconnected context-mechanism-outcome configurations: 1) knowledge and authority to respond to an unmet need; 2) role relevant training and opportunities for reflection; 3) clinical experts and senior staff promoting practices that are patient-focused; 4) engaging with opportunities to spend time with patients; 5) risk management as an opportunity for person-centred care; 6) valuing dementia care as skilled work. Effective interactions reduced patient distress and supported patient orientation. Training and allocation of staff time were of themselves insufficient to ensure dementia care was prioritised and valued as skilled work. Staff concerns about the consequences of adverse incidents and work pressures on the ward, even with support, took precedence and influenced the quality of their interactions with patients with dementia. A key finding linked to staff retention and developing capacity in the workforce to provide expert dementia care was that despite extra training and organisational endorsement, nursing staff did not regard dementia care as skilled nursing work.

Conclusions: There is increased awareness and organisational commitment to dementia-friendly healthcare in general hospitals. However, in addition to training and adapting the

1 environment to the patient, further work is needed to make explicit the specialist skills
2 required for effective dementia care.

3

4 **Keywords**

5 Case study

6 Dementia

7 Inpatient

8 Nursing

9 Person-centred care

10 Qualitative Research

11 Service Delivery

12

13 **Contribution of the Paper**

14 **What is already know about the topic**

- 15 • Caring for people living with dementia in hospitals is complex and requires a different
16 approach to caring for patients without a cognitive impairment.
- 17 • There has been increased activity within general hospitals to improve the care of
18 patients with dementia.

19 **What this paper adds**

- 20 • Despite significant investment and commitment from organisations, improving
21 dementia care provision relied on the actions of individual hospital staff who
22 recognised dementia care as fundamental to their role.
- 23 • Staff with knowledge in dementia care and authority to act, addressed patient needs
24 through advocacy and a pragmatic approach to balancing ward activities.
- 25 • Organisational priorities, such as patient safety, need to make explicit links to person-
26 centred care to reframe organisational concerns as opportunities to improve patient
27 outcomes.
- 28 • Realist evaluation can explain the differences in staff actions for care by identifying
29 conducive contexts that trigger mechanisms for change.

1 **Introduction**

2

3 The prevalence of dementia in people admitted to hospital is estimated at between 15% and
4 42% (Alzheimer's Society, 2009; Briggs et al., 2017; Sampson et al., 2009; Timmons et al.,
5 2015). Co-morbid conditions are common and dementia is rarely the primary reason for
6 admission (Alzheimer's Society, 2016; Bunn et al., 2014a). As such, dementia care is
7 considered a low priority and time consuming for hospital staff (Moyle et al., 2011). Patients
8 with dementia have an increased vulnerability to hospital-acquired complications compared
9 to patients without a cognitive impairment (Bail et al., 2013). Falls, infections, poor nutrition
10 and hydration, and delirium impact on the length of stay and functional abilities of patients
11 with dementia, which may result in a care home admission (Bail et al., 2013; Bunn et al.,
12 2014b; Orsitto et al., 2009; Richardson et al., 2016; Yevchak et al., 2017).

13

14 Improving dementia care in general hospitals is a policy priority (Department of Health, 2009;
15 Department of Health, 2015). While general hospitals are making progress in addressing
16 organisational issues, such as leadership, training, and the use of mental health liaison
17 services, staff and carers report variability in the impact of changes at patient level (Royal
18 College of Psychiatrists, 2017; Surr and Gates, 2017). Rigorous evaluations of interventions
19 to improve care provision for people with dementia are lacking (Dewing and Dijk, 2014;
20 Handley et al., 2017; Houghton et al., 2016). There is a need to understand how
21 interventions support hospital staff to provide dementia sensitive care, and with what
22 outcomes, for patients with dementia. Encouraging hospital staff to adapt the way they
23 provide care for patients with dementia is complex; multiple personal, social and
24 organisational factors will trigger different responses to interventions and, therefore, affect
25 outcomes.

26

27 *Programme theory*

28

29 Our realist review of interventions to improve hospital care for people living with dementia
30 (Handley et al., 2017) provided an explanatory account of how hospital staff could be
31 supported to provide good dementia care (see Table 3). This proposed that favourable
32 environments routinely reframed behaviours, such as agitation, as communication of an
33 unmet need and had an organisational culture that prioritised good dementia practice and
34 defined staff responsibilities for dementia care. In these circumstances, staff would
35 understand they had permission to adapt care for patients with dementia, recognise the
36 deficits of current care provision, and believe the approach was feasible leading them to
37 change the way they cared for patients with dementia. However, as empirical evidence was

1 largely descriptive, and there was limited evidence for patient outcomes further theory
2 testing was required. This study tested and refined the review findings through evidence
3 collected at two general hospitals where different approaches to supporting patients with
4 dementia were used. The aim was to explain the factors that support hospital staff to
5 provide dementia sensitive care and with what outcomes for patients with dementia.

6 7 **Method**

8
9 Realist evaluation is a theory-driven method of inquiry (Pawson and Tilley, 1997). It is an
10 approach for understanding how and why complex interventions (such as those which
11 depend on staff volition) work, or not, when applied in complex settings. Healthcare settings
12 are complex, involving multiple factors that will activate staff decisions for care. Realist
13 evaluation recognises the outcomes of interventions differ across settings and are context-
14 dependent. These variations are explained through mechanisms. Mechanisms are
15 conceptualised as the responses to resources inherent in interventions and are constrained
16 or activated in relation to context (Dalkin et al., 2015). A generative understanding of
17 causation underpins realist evaluation, with data collection and analysis focused on
18 uncovering the relationship between multiple factors, culminating in an explanation of what
19 works, for whom, and in what circumstances (Pawson and Tilley, 1997).

20
21 The scope of the evaluation was defined by the programme theory developed from the
22 review (Handley et al., 2017). This set out the circumstances (*context*), in which clinicians,
23 patients with dementia, and family carers respond to dementia-friendly interventions by
24 changing their reasoning (*mechanism*), that then leads to some or all of the outcomes of
25 interest (for example reduced patient distress, improved symptom control, family carer
26 satisfaction). The theory was tested in the two sites. Then through discussing and mapping
27 the recurrent themes in the data against our candidate theory we looked for patterns or
28 clusters of contextual factors that could give rise to particular practitioner responses (demi-
29 regularities). In team discussions we sought to explain further how the observed responses
30 might have arisen.

31
32 The selection of the two case study sites with differing approaches to dementia care
33 enabled us to test and refine the programme theory of features that support hospital staff to
34 provide dementia sensitive care and with what outcomes for patients with dementia (Yin,
35 2013). RAMESES II reporting standards for realist evaluations (Wong et al., 2016) guided
36 the development of this paper.

1 *Settings*

2

3 Our review identified a range of interventions used in hospitals to improve dementia care, for
4 example: training; the use of dementia champions; wards dedicated to care for patients with
5 dementia; and the use of biographical tools (Handley et al., 2017). However, the review
6 argued that single initiatives alone were insufficient and that organisational endorsement for
7 dementia care practices was key. We purposively selected two NHS Trusts in the East of
8 England where substantial financial investment into services for patients with dementia had
9 been made. This investment was considered indicative of the organisations' commitments
10 to improving care for patients with dementia. By understanding the processes in these
11 environments, which promoted best practices with patients with dementia, the study could
12 focus on testing the programme theory against the evidence (Emmel, 2013). Provision had
13 been applied differently: site 1 had a ward that provided care for patients with dementia with
14 medical and mental health needs; site 2 had developed a team of healthcare assistants who
15 had support from dementia specialist nurses to provide one-to-one care for patients with
16 dementia across the hospital. This allowed testing in different contexts of care and
17 increased the potential generalisability of the refined theory.

18

19 *Recruitment and participants*

20

21 Hospital staff, patients with dementia, and family carers were recruited at both sites by one
22 of the authors (MH). All staff working on participating wards (site 1 and 2), staff from the
23 dementia support team (site 2), and patients admitted to participating wards were given
24 verbal and written information about the study, including forms to opt-out of observation
25 sessions. Posters were displayed in the wards to remind people observations were taking
26 place. Recruitment was ongoing throughout data collection and participants were made
27 aware that their involvement was voluntary and could be withdrawn. On the day of an
28 observation period, verbal agreement to participate was sought from staff and patients
29 located in the observation area. Ongoing consent was assessed and used with all patients
30 with dementia during data collection. Data were anonymised in field notes and no personal
31 information was collected for staff, patients or visitors.

32

33 Staff were eligible for interview if they worked with inpatients with dementia. Staff with
34 different roles (healthcare assistants, nurses, medical staff, allied healthcare professionals,
35 and support staff) and different priorities in patient care (strategic, management, frontline)
36 were invited for interviews to contribute to theory testing and refinement (Manzano, 2016).

37

1 Patients were eligible if they had a diagnosis of dementia or were identified by staff or family
2 members as thought to have dementia. Patients were excluded if they were receiving end of
3 life care. At site 1, patient recruitment was restricted to those transferred to the dual-frailty
4 ward and all eligible patients were invited to participate in the study. At site 2, patients with
5 dementia were recruited across the hospital. Eligible patients were identified by a senior
6 nurse and recruited by the researcher (MH). For recruitment to interviews, patient notes
7 review, and assessment of patient behaviour and mood during their admission using the
8 Neuropsychiatric Inventory Questionnaire (NPI-Q) (Kaufert et al., 2000), participants were
9 provided with verbal and written information at least 24 hours before deciding whether to
10 participate. For patients with dementia, capacity to consent followed the Mental Capacity
11 Act (Department of Health, 2005). All patients were assumed to have capacity to consent
12 unless discussions with staff and the patient suggested otherwise. Where capacity was
13 lacking, a personal consultee was identified who, based on their knowledge of the patient
14 and their likely preferences, could provide for assent to the study. Where no personal
15 consultee was identified, a nominated consultee was used. Ethics and governance approval
16 were gained (East of England - Essex Research Ethics Committee 16/EE/0263).

17

18 *Data Collection and procedures*

19

20 Data collection was conducted by MH between October 2016 and March 2017; seven weeks
21 at each site. Methods included interviews, non-participant observations, medical notes
22 review, assessment of mood and behaviour using the Neuropsychiatric Inventory
23 Questionnaire (NPI-Q) (Kaufert et al., 2000), and documentary review. Data collection
24 focused on the anticipated outcomes from dementia care interventions, for example staff
25 actions for care and patient outcomes such as reduced distress and symptom management.

26

27 *Interviews*

28 Interviews with staff provided data to help understand the context of care. For example, their
29 role in patient care and balancing multiple patient needs. It was also used to test the context-
30 mechanism-outcome configurations (CMOCs) from their perspective. Using a teacher-
31 learner cycle (Manzano, 2016), the theory was explained to the interviewee and explored
32 what they agreed with, refuted, or were unsure about. This approach to interviewing
33 developed the theory based on their experience with questions informed by the review
34 findings and emerging theories. For example, interviews probed new ideas related to staff
35 concerns that working predominately in dementia care might hamper their career
36 progression. Interviews with patients and family members were predominantly focused on

1 outcomes from staff actions for care, such as their experience of staff support for personal
2 care.

3

4 *Non-participant observation*

5 Non-participant observations using a topic guide took place in patient bays on the wards
6 (Bryman, 2012). Data collection focused on the context of care, such as the environment,
7 staff mix, ward routines, and how staff actions impacted on patient outcomes, such as
8 whether a strategy reduced a patient's distress. The purpose was to form a comprehensive
9 understanding how different ward routines, patient needs and staff mix could impact on staff
10 actions for patient care and patient outcomes Field notes were handwritten during
11 observations and transcribed by the researcher at the earliest opportunity following data
12 collection. Conversations with staff and patients before each observation session revealed
13 factors such as patients' clinical, social and personal needs, plans for organised activities,
14 and the use of additional staffing resources (or not). This information was considered with
15 reference to the programme theory and how it expanded, challenged or refined
16 understanding about what improved (or not) patients' experience of care. The decision for
17 the location and focus of an observation session was based on this criteria. In Site 1,
18 observations were limited to the participating ward. In Site 2, decisions were based on
19 whether there were eligible patients in the patient bays.

20

21 *Medical notes, NPI-Q and documentary review*

22 Data from patient notes were extracted and anonymised using a data collection form which
23 included; reason for admission, co-morbid conditions, medication use, and evidence related
24 to staff observations of patient behaviours, needs, and their actions for care. Along with data
25 from the NPI-Q, this illustrated the patients' characteristics. NPI-Q was administered by one
26 of the authors (MH) or a clinician to the patient's family carer. Documents at each site, such
27 as policies related to dementia, annual reports, and assessment tools, provided data about
28 the organisational context.

29

30 *Analysis*

31

32 In realist evaluation, analysis is consciously theory-driven and draws on deductive, inductive,
33 and retroductive strategies. A theory-driven approach to thematic analysis (Braun and
34 Clarke, 2006) was used to identify demi-regularities and the linked components of CMOCs,
35 to extend or refute the programme theory from the realist review (Handley et al., 2017).
36 Qualitative data from interviews, observations, medical notes, and organisational documents
37 were imported into NVivo 11 (QSR International). Eight parent nodes were defined that

1 represented: a) the six CMOCs from the realist review; b) a developing CMOC identified
 2 during data collection around valuing dementia care; and c) a node for unrelated data. All
 3 qualitative data were initially coded in sections, ranging from a sentence to a paragraph, to
 4 at least one parent node. The relevance of data to each CMOC was that it provided partial
 5 or complete data about the relationship of the elements of the CMOC. Data were then
 6 inductively coded within each CMOC to reflect dyads (for example, context-outcome,
 7 context-mechanism, mechanism-outcome) and triads (context-mechanism-outcome) that
 8 would extend and refute current CMOCs. Coding was completed by one author (MH) and
 9 regular meetings with the research team (FB, CG, MH) were used to debate and challenge
 10 interpretations against the evidence and propose alternative explanations. Challenges were
 11 recorded as memos in NVivo to track the analytic process and data were further interrogated
 12 to test alternative accounts. Evidence was examined until interpretations were agreed.
 13 Biannual meetings with Research Network Monitors from the Alzheimer’s Society were used
 14 to share, dispute, and validate the initial, developing, and final CMOCs. The Monitors (PM,
 15 RP, JW), were volunteers with experience of caring for a family member with dementia.

16

17 Quantitative data collected from patient notes, such as length of stay, and NPI-Q data were
 18 analysed in SPSS 24 (IBM Corp, 2016). The data were used to provide contextual
 19 information of the recruited patient population through descriptive statistics.

20

21 **Findings**

22

23 Sixty-six participants were recruited to the study; 36 staff, 28 patients (4 who participated in
 24 interviews), and 2 family members (table 1). Eighty hours of non-participant observation
 25 were conducted between the hours of 7am and 10pm; 41 hours at site 1 and 39 hours at site
 26 2.

27

28 Table 1: Participant recruitment by site

Role	Site 1	Site 2
Staff participating in interviews		
Healthcare assistants	3	7 (2 ward, 5 from one-to-one team)
Nurses (bands 5 – 7)	7	7
Allied Health Staff	2	1
Medical staff (doctors and psychiatrists)	4	3

Housekeepers	0	2
Patients recruited for notes review (patients interviewed)	18 (2)	10 (2)
Carers interviewed	1	1
Total participants	35	31

1

2 A total of 69 patients with dementia across the sites were eligible to participate in the study.
3 Twenty-eight were recruited, this included seven patients out of 19 with the capacity to
4 consent and 21 out of 50 where a consultee process was used. Patients with dementia with
5 capacity to consent and nine consultees who declined involvement considered the study was
6 not something they wanted to take part in or that their experiences were not relevant to the
7 study. Twenty consultees did not reply to study information.

8

9 Patients recruited at site 1 were younger than those at site 2 (table 2). Overall patients from
10 both sites had a similar length of stay, although nine patients at site 1 stayed longer than the
11 median. At site 1, 50% of patients returned to their original place of residence, at site 2, this
12 was 30%.

13

14 Table 2: Patient characteristics

	Site 1 (n=18)	Site 2 (n=10)
Median Age years (range)	77 (range 62 – 92)	88 (72 – 99)
Gender Male / Female	11 / 7	4/6
Length of stay days (range)	21 (4 – 106)	23 (12 – 42)
Place of admission:		
Own home	11	8
Residential Home	2	2
Nursing Home	3	0
Sheltered Housing	1	0
Other Hospital	1	0
Place of discharge:		
Own Home	4	1
Residential Home	4	4
Nursing Home	6	3
Sheltered Housing	1	0
Hospital (rehabilitation)	0	1
Mental health	2	0
RIP	1	1
Number returning to same place of residence yes/no/RIP	9/8/1	3/6/1
Reason for admission		
Fall	4	3
Confusion	6	0
Infection	5	3

	Site 1	Site 2
Fracture	0	4
Cardiac/respiratory	3	0
General decline	0	2
Formal Dementia Diagnosis Yes/No	9/9	10/0
Dementia Type		
Alzheimer's Disease	4	1
Vascular Dementia	3	3
Mixed Dementia	0	2
Lewy Bodies	1	0
Unspecified	1	4
Delirium Yes/No	8/10	1/9
Comorbid conditions (range)	Median 5 (1 – 13)	4.5 (1 – 11)
Number of medications on admission (range)	Median 9 (3 – 15)	11 (4 – 26)
Recorded adverse incident during stay Yes/No	12/7	3/7
NPI-Q median number (range)	3 (0 – 7) (n=17)	Median 2 (0 – 5)
Delusions	5	1
Hallucinations	5	2
Agitation or aggression	14	6
Depression or dysphoria	5	2
Anxiety	3	4
Elation or euphoria	0	0
Apathy	1	0
Disinhibition	1	0
Irritability or Lability	2	2
Motor disturbance	8	1
Night time behaviours	9	2
Appetite or eating	0	2

1

2 The programme theory from the realist review comprised six inter-related context-
3 mechanism-outcome configurations (CMOCs i - vi) for how staff in general hospitals are
4 supported to provide dementia sensitive care. Each of these propositions were taken
5 forward to the realist evaluation for testing and refining from data collected at the case study
6 sites. Some CMOCs from the review were merged and a new CMOC (valuing dementia
7 care) developed (table 3). The refined CMOCs and example data are described below.

8

9 Table 3: Context-mechanism-outcome configurations from the realist review and refined
10 configurations from the realist evaluation

Initial CMOCs developed during the realist review	Refined CMOCs from realist evaluation
i) Understanding behaviour as communication improves staffs' ability to respond	1) Knowledge and authority to respond to an unmet need

ii) Experiential learning and empathy encourages reflection on responsibilities of care	2) Role relevant training and opportunities for reflection
iii) Clinical experts who legitimise priorities for care	3) Clinical experts and senior staff promoting practices that are patient-focused
iv) Staff with confidence to adapt working practices and routines to individualise care	4) Engaging with opportunities to spend time with patients
v) Staff with responsibility to focus on psychosocial needs	
vi) Building staff confidence to provide person-centred risk management	5) Risk management as an opportunity for person-centred dementia care
	6) Valuing dementia care as skilled work

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CMOC 1: Knowledge and authority to respond to an unmet need

Where patient behaviours, such as agitation, are understood by nurses and healthcare assistants as communication of an unmet clinical, physical, psychological, or social need (context), and they have knowledge of the patient and good practice in dementia care (mechanism resource), staff may feel they have the capacity, capability, and authority to influence the situation (mechanism reasoning). They may be more likely to consider and respond to the underlying causes of the behaviour (staff outcome) leading to the patient's need being met (patient outcome).

Staff were observed to draw on two main methods for identifying and addressing patient needs: systematic and intuitive approaches. Systematic recording of dementia-related care and patient expressions of need were linked to staff's belief that they had the capacity, capability and permission to respond and improve a patient's situation. When staff identified the underlying cause for a patient's behaviour and knew how to adapt care, this knowledge and action required was shared to address the patient's needs. As this excerpt demonstrates the healthcare assistant recognised the importance of noting patient preferences and took responsibility to ensure this was documented:

1 [FN: Alice earlier reacted badly to being supported with personal care by a male
2 member of staff.] The healthcare assistant comments that she will go and update the
3 nurse and ward manager **and put it in the patient notes that Alice is not to have**
4 **male support.** (Site 2, OB0202)
5

6 However, when staff did not identify a patient's needs and possible reasons for distress or
7 were not encouraged to share information, recordings of the patient's negative reactions and
8 the strategies attempted by staff were inconsistent. This was particularly apparent for
9 behaviours such as verbal agitation when compared to more physically disruptive and high-
10 risk behaviours. Verbal agitation, such as repeated calling out, was recognised as disruptive
11 and indicative of patient distress, but the review of medical notes suggested this kind of
12 behaviour was unlikely to be systematically recorded, assessed, discussed with family
13 members or reviewed. The dominant view from ward staff was that verbal agitation was
14 inevitable and intractable, leaving them feeling unable to influence the situation. As this
15 quote demonstrates, there was an awareness that a person's biography could help resolve
16 difficulties but if this was unknown staff options could be limited:

17
18 "So we don't know anything about her and all we see is this person constantly calling
19 out and bashing, who won't comply with anything." (Site 2, ST0219, Senior Ward
20 Nurse)
21

22 In addition to staff having the capacity and capability to feel they could influence the
23 situation, observations demonstrated the importance of staff needing to feel they had
24 authority to act. Authority was not always linked to seniority but could be triggered in more
25 junior staff by a belief that prioritising dementia care was part of their role. For example,
26 considering they had the authority to act might lead them to resist other demands on the
27 ward to take time and sit with patients needing reassurance. Knowledge was also an
28 important resource that staff drew on. Healthcare assistants observed (and recognised by
29 peers as having these skills) to work well with patients with dementia discussed how they
30 drew on knowledge in dementia care developed from training, professional and personal
31 experiences. It was difficult to know if a prior awareness and interest meant that some staff
32 would be more receptive to training than others. This quote illustrates how a training course
33 had heightened staff awareness to pain as a possible cause of agitated behaviour and could
34 be used to address the patient's need:
35

36 The one-to-one said since she had attended a training course on pain and dementia
37 she has been 'on it' looking out for evidence of pain.... She explains that John had

1 been very agitated this morning and was constantly trying to get out of bed and
2 pulling his catheter, but since he has had the pain relief he has been much calmer.
3 (Site 2, OB0213)

4
5 In contrast, other healthcare assistants working in the same units who had the same
6 opportunities to learn often did not consider they had the authority to influence the situation.
7 This was evident in their actions, for example, ignoring the patient or repeated brief
8 interactions.

9
10 *CMOC 2: Role relevant training and opportunities for reflection*

11
12 *Where there were opportunities for training and sharing skills (context) staff can*
13 *develop a range of techniques relevant to their work (mechanism resource). By*
14 *recognising the limitations of their current skills and through a desire to know they are*
15 *‘doing the right thing’ (mechanism reasoning) staff will be more likely to engage with*
16 *learning opportunities and apply methods to their work they have observed as*
17 *successful (outcome).*

18
19 The review identified that experiential training that triggered empathy in staff for patients with
20 dementia was important for encouraging reflection on current working practices and
21 understanding why care should be modified. This theory was discussed with those providing
22 and receiving dementia training. Trainers agreed that developing staff’s empathy for people
23 with dementia could help them recognise that practices common with patients without
24 cognitive impairments needed adapting:

25
26 “things like how we maybe need to take a step back and think about how we would
27 feel if we were in a strange environment with strange people coming to help us to do
28 extremely personal care tasks.” (Site 1, ST0111, Allied Healthcare Professional)

29
30 In contrast, trainees reported that developing practical, dementia specific skills that were
31 relevant to their work would help them apply the principles to their practice. For these staff,
32 developing a framework of responses that would support their work with patients was linked
33 to the mechanism that they ‘knew they were doing the right thing’:

34
35 “[training] For some people, just how to act around a dementia patient, you know,
36 when they are asking for their parents, you know, just to give them tips.” (Site 2,
37 ST0205, Healthcare Assistant)

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Nurses and healthcare assistants reported they were aware of limitations of their knowledge and strategies to support patients, and this was a motivating factor in engaging with learning opportunities:

“when someone has more experience, and so you can understand how, for example, a colleague is able to manage medication with the patient. It is interesting to learn, something like trying to get more knowledge.” (Site 1, ST0102, Nurse)

Observational data suggested that peer learning was especially instrumental in helping staff develop a framework of different strategies:

A healthcare assistant goes over to her “hello Edith, how are you today?” They have a brief chat, then the healthcare assistant walks away from the bed and speaks to another healthcare assistant saying “I’m going to get her some finger food for breakfast. She ate that well yesterday.” (Site 1, OB0109)

However, if approaches were not informed by an understanding of best practice in dementia care, learning by this method could lead to the collective use of poor practices. Examples were observed where ward routines were prioritised over supporting patients’ preferences and abilities, for example relying on commodes or pads rather than assisting patients to walk to the toilet and restricting patients in their bed area.

CMOC 3: Clinical experts and senior staff promoting practices that are patient-focused

Where standards for dementia care are defined, monitored and reinforced (context) by clinical experts in dementia care and managers who work in close proximity to staff and are regarded by those staff as credible (mechanism resource), staff may consider they have the permission to adapt care (mechanism reasoning) and provide care in ways that benefit patients with dementia (outcome).

At both sites, medical, nursing, and allied healthcare professionals with clinical expertise in dementia care had developed hospital policies for the care of people with dementia based on national guidance. These policies set out the expectations for patient care, clarifying assessments and processes, and legitimising best practice procedures with the aim of improving the consistency and quality of dementia care. However, the impact of these policies at patient level was not clear and routinely collected outcome data were limited to

1 measures common to other patient groups, such as falls and pressure sores. There was no
2 indication of the impact of recommendations on incorporating biographical information in
3 care plans or the use of dementia sensitive assessment tools, such as the Abbey Pain scale
4 (Abbey et al., 2004).

5
6 “I suppose at the moment **there is no physical, no way to show that we are giving**
7 **good care**. We have the care plan about the standards we have to follow which
8 could be one of the best ways to measure it.” (Site 2, ST0201, Senior Nurse)

9
10 To ensure compliance with dementia care policies, clinical experts in dementia care provided
11 training in assessment and care planning tools and audited how this information was applied
12 in practice. This reinforced expectations for patient care and was thought to help staff to
13 consider strategies to better support patients with dementia:

14
15 [Discussion of auditing ‘*This is me*’ across the hospital. Monitoring how reasonable
16 adjustments have been applied to incorporate patient preferences.] “This patient
17 gets up early, what have you put in place. Or they go to bed early, have you made
18 sure any drugs that need to be given before that time.” (Site 1, ST0114, Senior
19 Nurse)

20
21 Clinical experts understood, that in order to influence staff behaviour, they needed to be
22 seen as a credible, trusted resource. Credibility was understood as a quality gained through
23 occupational background and professional experience with patients with dementia:

24
25 [Training in working with patients with behaviours that challenge staff.] “So one of
26 our [psychiatric ward] nurses who has been there and done that as an inpatient
27 nurse... So when she tells you to do ‘X’ she is doing it from experience.” (Site 1,
28 ST0116, Medic)

29
30 However, clinical experts’ proximity and level of contact with ward staff was influential in
31 whether guidance was sought or used. Clinical experts acknowledged the priorities set by
32 senior ward staff were more likely to influence actions taken by nurses and healthcare
33 assistants:

34
35 “Because there was this general feeling, you know ‘who is this person on the ward
36 with a note pad and says these are the stuff you have to do’.” (Site 2, ST0218, Senior
37 Nurse)

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Ward staff at site 1, who received regular input from clinical experts, were able to describe the differences in care provision on other hospital wards and the impact this had on patients:

On other wards they are trying to keep all the patients in their bed, that's not right. The patients are confused, and they are trying to keep them in the bed. They become more confused, more agitated. (Site 1, ST0102, Nurse)

Advice on best practice for patient care from clinical experts who had limited contact with a ward needed to align with the priorities set by senior ward staff.

CMOC 4: Engaging with opportunities to spend time with patients

Where there is endorsement for dementia care practices and a clear understanding of staff responsibilities for patient care (context), patients' dementia related-needs may be legitimately prioritised over other ward activities (mechanism resource) and staff may recognise their work as equally contributing to that of their colleagues (mechanism reasoning) enabling them to spend time with patients for reassurance and provide activities (outcome) that reduce patient anxiety and boredom (outcome).

CMOCs iv and v from the review (see Table 3) were conceptualised separately in the original programme theory. However, as part of the realist evaluation the CMOCs were merged and refined.

Endorsement for dementia care practices, whether from the organisation through defined roles in patient care or from colleagues who reinforced the social norms for patient care, had an impact. For example, this effected whether healthcare assistants and nurses spent time with patients with dementia who appeared anxious or bored. Providing activities for patients with dementia required good interpersonal skills. Staff needed to understand the interests and abilities of the patient, interpret the patient's non-verbal behaviour, recognise their changing needs, and respond appropriately. This was observed to reduce expressions of anxiety or distress in patients.

[FN: Olive has been anxious about where she is for some time]. The healthcare assistant encourages Olive to do a word search by starting to look through the book and then sitting close to Olive saying, "let's find this word together". She hands Olive the book and starts to help her look for the word. When Olive finds the word, she

1 congratulates her and helps her to cross the word out to the right point by holding her
2 finger to the end of the word. She continues to sit and help Olive to look for words,
3 talking through the strategies. Olive and the healthcare assistant are both focused
4 on the activity for some time, Olive does not appear distressed and is concentrating
5 on the activity. (Site 2, OB0205)

6
7 Activity staff and one-to-one team members for patients with dementia recognised the
8 contribution they made to the patient. Having a clearly defined role for patient care
9 legitimised actions that prioritised the needs of one patient over other ward activities. This
10 was despite psychological and social pressures to be more broadly involved in the work on
11 the ward:

12
13 “I do want to help out and look after the patients and keep everybody happy and help
14 the ward but you can’t do everything. You are there for a specific job and purpose
15 and that’s got to [be your priority], because otherwise once you start doing too much,
16 they will give you other jobs to do.” (Site 2, ST0203, One-to-one)

17
18 However, in the busy ward environment, it was difficult and an ongoing battle to reconcile
19 this with the observed ward pressures, especially when the extra support of the one-to-one
20 team was not available:

21
22 “They [one-to-one team] are not here today. So that means that the nurses are put
23 upon, because I’m not free to care for the other patients.” (Site 2, ST0202,
24 Healthcare Assistant)

25 26 *CMOC 5: Risk management as an opportunity for dementia care*

27
28 *Where staff allocated to monitor a patient’s safety (context), draw on their knowledge*
29 *of dementia care and the patient (mechanism resource), concerns for the potential*
30 *consequences to themselves and the patient (mechanism reasoning) informed how*
31 *staff engaged with monitoring activities (outcome) and whether patient choices and*
32 *mobility were supported (patient outcome).*

33
34 Patient safety was a priority at both sites and patients perceived at significant risk of harm,
35 either to themselves (e.g. a fall) or others, were allocated healthcare assistants or one-to-
36 one staff to sit with them. Staff assigned to these roles were observed to react in one of two
37 ways: 1) to engage with person-centred approaches that enhanced the patient’s experience,

1 or 2) to restrict movement but not engage further with the patient. These are illustrated in the
2 following two examples.

3
4 Bob and a healthcare assistant are sat together completing a puzzle. The healthcare
5 assistant says, "let's look for the edges first". She prompts him to make the right
6 selection of pieces to go together with suggestions for pieces that might fit the area
7 he is working on and moving pieces close to other relevant pieces. They continue to
8 complete the puzzle together for half an hour. (Summary of Site 1, OB0106).

9
10 Ruth tries to stand and the healthcare assistant puts her hand out to encourage her
11 to sit down. Ruth bats the hand away and complains about not being allowed to get
12 up. The healthcare assistant rolls her eyes at me. She does not engage with Ruth
13 beyond putting out her hand to stop her from standing and telling her she needs to
14 sit. (Site 2, Summary of OB0213).

15
16 Staff observed to use approaches that enhanced a patient's experience during monitoring
17 activities explained how distraction and engagement could calm the patient. This could
18 reduce the complications that arose from behaviours linked to the patient's anxiety and
19 distress:

20
21 "if you interact with them, you attempt to do the things. Connect 4, I played connect 4
22 with somebody the other day, and they knew exactly how to play it. And yet normally
23 they're pulling out their fluids." (Site 2, ST0215, One-to-one)

24
25 Healthcare assistants also discussed dilemmas around supporting patients' choices while
26 managing their risks. Concern for the consequences of an adverse incident often led staff to
27 act in a more risk averse manner, for example using bedrails despite patients requests not
28 to:

29
30 [Margaret is sleeping.] The healthcare assistant reports that Margaret had said earlier
31 she does not want the bedrails up and while the healthcare assistant understands
32 her choice, she is still not comfortable with it. She apologises to Margaret but says
33 that she is going to put the bedrails up for safety. She puts them up and then pulls
34 the curtains around Ann to help her with personal care. (Site 2, OB0212)

35
36 Support for patient mobility was observed to be differently prioritised at the sites, despite
37 clinical experts at both sites articulating the importance of maintaining patients' functional

1 abilities. At site 2 support for mobility was limited to personal care tasks. At site 1, where
2 clinical experts in dementia care worked closely with ward staff and promoted an enabling
3 approach to patient care, patients able to mobilise without the support of staff walked around
4 the ward and spent time in areas of their choice. As this quote demonstrates, it required a
5 different mindset and support for both staff and patients to accommodate patient needs:
6

7 “It’s like Albert might wander into the female bay, it’s no great headache down there.
8 It’s like “oh Albert is here again.” However, if you had that on the acute ward it would
9 be “what’s he doing in the female bay?”” (Site 1, ST0114, Senior Nurse)
10

11 *CMOC 6: Valuing dementia care as skilled work*

12

13 *Where dementia care is valued as core work (context) and good practice in dementia*
14 *care and staff development are prioritised, (mechanism resource) staff may*
15 *recognise dementia care as skilled and fundamental to their role (mechanism*
16 *reasoning) leading them to continue to expand their skills and commit to working in*
17 *dementia care (outcome).*
18

19 CMOC 6 was identified early in the realist evaluation as an important, overarching concept.
20

21 Nurses and healthcare assistants who valued dementia care recognised dementia care as
22 skilled work, could articulate their contribution to patient care and how it was making a
23 difference to patients, and expressed satisfaction with the work.
24

25 “I think sometimes, because they [patients with dementia] don’t know what they do or
26 where they are and where everybody is. And to sit down with them and chatting with
27 them, really calming and talking to them in an ordinary way. And with the card game
28 you could tell he just changed, from this confused man to sort of “oh I like things like
29 that.” And it was great, it was good to see that.” (Site 2, ST0215, One-to-one)
30

31 Clinical experts discussed the importance of training and education to reinforce these skills:
32

33 “So these things you could say they are basic common sense, but at the same time
34 they are things that you need to teach people and reinforce as part of good practice.”
35 (Site 1, ST0116, Medic)
36

1 However, some staff did not appear to value spending time with people with dementia, for
2 example to provide reassurance, reduce anxiety, and maintain safety, because it was not
3 seen as real or skilled work.

4
5 “I don’t think it’s a skill, you just ensure that you don’t let them fall, that’s it.” (Site 2,
6 ST0202, Healthcare Assistant)

7
8 At a service level, ward staff appreciated staff who worked predominantly with patients with
9 dementia when they went beyond the remit of their role and took on additional ward
10 activities. Thus, from the outset the benefits of providing one-to-one attention were
11 devalued:

12
13 “Some one-to-ones come on to shift and are very good, they help out with other
14 patients in the bay if the patient they are working with is resting or calm. Other
15 members of the one-to-one team only work with the person they are assigned to.”
16 (Site 2, ST0220, Senior Ward Nurse)

17
18 In site 1 patients tended not be in the acute phases of an illness. This impacted on staff
19 retention because some nurses worried that they were becoming deskilled:

20
21 [Summary of conversation with senior ward nurse] She was losing seven nursing
22 staff by the end of the year. Some were moving to jobs in A&E and she accepted
23 that nurses who had recently qualified wanted to be in a more clinically focused area
24 so they would not lose their clinical skills. (Site 1, OB0109)

25
26 This concern at losing care skills was not limited to qualified staff. Some healthcare
27 assistants working in the one-to-one team felt the focus on risk management reduced their
28 involvement in other care tasks that they considered skilled work:

29
30 “I’d been hoping actually that I’d be learning new things, but I feel like I’ve lost a lot of
31 my skills.... for example, in the hospice I changed a lot of stoma bags, and things like
32 that.” (Site 2, ST0211, One-to-one).

33
34 The majority of dementia care at both sites was provided by healthcare assistants.
35 However, there appeared to be no formal recognition or reward for healthcare assistants

1 who demonstrated enhanced dementia care skills. This lack of recognition may have
2 impacted on whether they defined their work as skilled:

3

4 “I think a lot of the time they [healthcare assistants on ward] do a lot of really good
5 work, but they don’t really realise that they’ve got of skills that a lot of other
6 healthcares don’t.” (Site 1, ST0111, Allied Healthcare Professional)

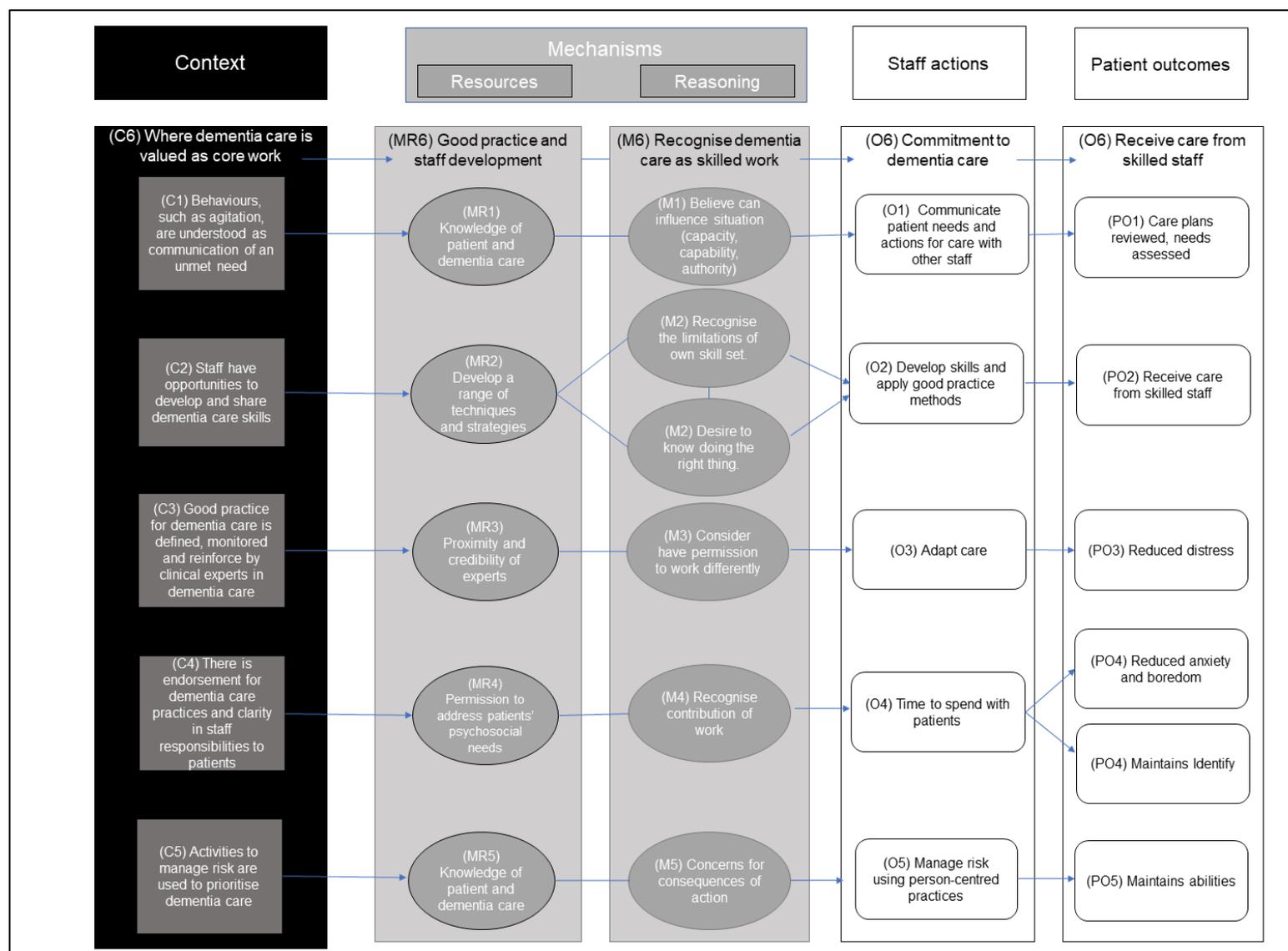
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8 *Summary of the CMOCs*

9

10 Findings indicated a key context for supporting the provision of good dementia care and
11 improving outcomes for patients with dementia was how dementia care was valued by staff
12 and the employing organisation. This triggered what staff understood to be core work, which
13 influenced how they responded to patients’ needs. Care activities that allowed staff
14 additional time with patients with dementia could legitimise dementia care work. However,
15 how staff engaged with these activities was contingent on whether staff considered this was
16 an opportunity to enhance care, or less of a priority than other ward demands. Reducing
17 patient anxiety and distress was observed when staff had the authority to resist other
18 demands and influence action that would address a patient’s unmet need (Figure 1).

Figure 1: Refined programme theory of factors that support staff to provide dementia sensitive care and with what outcomes for patients with dementia



Discussion

How dementia care was valued influenced whether dementia care was recognised as skilled, core work. These ideas have been accepted as central to improving the provision of dementia care across care settings (Brooker, 2007; McCormack et al., 2011; McCormack and Watson, 2017). What this study contributes is an account of how different staff working within the same unit valued dementia care in different ways. Experiential learning, staff experience, and peer-to-peer learning reinforced good practice, complemented training, and provided a counter narrative to the very real pressures of ward routines and priorities. Identifying and rewarding those within the staff team who are intuitively and systematically addressing the dementia care needs of patients has the potential to challenge practices that consider psychological, social, and emotional needs as too time consuming (Clissett et al., 2014; Featherstone and Northcote, 2018; Pinkert et al., 2017).

Healthcare assistants provide the majority of essential care for the most complex and vulnerable patients, however recognition of their skills and contributions to patient care is often not acknowledged (Scales et al., 2017). Providing healthcare assistants with opportunities to share their experiences of what has worked well will help them to recognise their skills in dementia care and consider alternative approaches from their colleagues. Additionally, healthcare assistants should have access to ongoing development in dementia care, such as communication skills (O'Brien et al., 2018) and person-centred care (Surr et al., 2016), that has relevance to their work. Understanding that these skills are valuable and core to their work increases the likelihood of healthcare assistants being more willing to apply them during their interactions with patients with dementia. Accredited training schemes that reinforce the message that dementia care is skilled work and creates a clear career progression can further promote the important contribution of their role in patient care. To ensure clarity and consistency in the expectations and priorities for dementia care and reinforce staff training and education, ward managers should work with clinical experts in dementia care to develop their own knowledge and confidence in promoting and valuing dementia care skills and practices.

Managing risk in patients is an important element of patient care, however there is a contradiction around how risk is often managed in patients with dementia. While organisations place considerable emphasis on patient safety, the activity itself is often afforded little value: allocation of these duties is often to junior, inexperienced staff who focus on restricting movement (Dewing, 2013; Moyle et al., 2008). Monitoring activities are common for managing risks and provide staff opportunities to enhance patient care (Wood et

al., 2018). A recent feasibility study of protected engagement time with older patients found no reduction in incidents of adverse events, such as falls or violence and aggression (Smith et al., 2018). However, the study did not collect data for how staff and patient interactions took place or patients' reactions to the input, which may have had implications for clinical outcomes. Our study demonstrated that staff tasked with closely monitoring patients with dementia carried out the activity differently depending upon the knowledge they drew on and how they interpreted the wider contribution of this work. Potentially, ward-base staff development in dementia care that aligns with patient safety activities may address these concerns.

Understanding what motivates staff to commit to working in dementia care needs further research (Chenoweth et al., 2014). However, one factor identified in this study was the difficulty for nurses to define their expertise and technical competency in situations where there were limited opportunities to differentiate their work from that of healthcare assistants. Other studies have highlighted that staff need specific skills in dementia care that go beyond an understanding of person-centred care, for example in communication and enabling people with dementia to accept help with personal hygiene and be continent (Buswell et al., 2017; O'Brien et al., 2018). Failing to recognise dementia care as skilled specialist work may lead nurses to feel their role in patient care is threatened (Daykin and Clarke, 2000). Studies in general hospitals have found nurses and healthcare assistants define their professional identity in opposition to each other (Kessler et al., 2010; Schneider et al., 2010). Interventions that can nurture a group identity around the goals for patient care while recognising the value and specific contribution of other professional groups could provide a way to address this and has shown promise in one care home study (Amador et al., 2016).

Strengths and limitations

This realist evaluation used a theory developed from the existing evidence base and tested and refined it in case study sites with different cultures for dementia care. The same mechanisms were found to operate at both sites and explained the different effects on staff actions and patient outcomes. Their influence was evidenced through positive and negative examples in the data. Potentially, this increases the transferability and usefulness of the findings beyond the local context, which could be used to improve intervention design and acceptability.

During analytic process, mechanisms were identified as resources inherent in the intervention and the reasoning of staff (Dalkin et al., 2015). This helped distinguish concepts

as context or mechanisms, a difficulty encountered by other researchers when applying the methodology (Greenhalgh, 2009; Marchal et al., 2012). However, there was still considerable debate between authors when defining the component parts. For example, we considered that ‘time to spend with the patient’ could be conceptualised differently depending on the role it performed in the CMOC, i.e. whether it caused the outcome, triggered the mechanism, or was the observable result.

Recruiting family carers was problematic. While 21 family carers were approached for interview, only two participated. A number of factors contributed to this including the emotional impact of their relative’s admission, increased restraints on time due to hospital visits and organising discharge arrangements, and practical concerns, for example the cost of hospital car parking. Other studies of people living with dementia admitted to hospital have found similar difficulties with recruitment of family carers (Clissett, 2013; Closs et al., 2016). As such, the experiences of the Research Network Monitors helped to attend to this gap in the evidence.

It was not possible from this study to understand how staff actions influenced patients’ clinical outcomes. An RCT of a medical and mental health unit in a hospital, where best practice principles for dementia care were employed, demonstrated minimal improvements in health status outcomes but positive outcomes in terms of patient wellbeing and carer experience (Goldberg et al., 2013). In our study, we observed that patients’ experience of care was influenced by how dementia care was valued in the ward environment and how this influenced what care activities staff prioritised.

Conclusion

Improving dementia care in general hospitals continues to be a high priority. The focus needs to develop further from standalone interventions and episodes of training to how dementia care can be integrated into the work of hospital staff. Even in settings with staff trained in dementia care it cannot be assumed that practitioners or the organisation recognise that this is skilled work. Dementia care needs to be recognised as core work by senior ward staff and organisational management and be rewarded in line with clinical work. Staff concerns around how dementia care work contributes to the collective work on the ward need to be addressed at the practitioner/patient and leadership levels of care delivery. One way forward could be to align staff development in dementia care and its values with organisational priorities.

Conflict of interest

None.

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