



An ethnographic study of family involvement in the general hospital care of people with dementia

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Background to the study...



1 in 4 people in general hospitals have dementia...



...and they have worse experiences and outcomes of care than people who do not have dementia





A few facts...

50% of people with dementia are undiagnosed on admission to hospital

2-4 times more likely to die in hospital if you have dementia

Sampson et al, 2009

92% of carers reported their loved one found the environment frightening

33% of people with dementia who are admitted to hospital never return home

People with dementia stay **twice as long** in hospital as people without dementia

Counting the Cost, Alzheimer's Society, 2009



Essentially...

'Poor care in hospital can have devastating, life-changing consequences for someone with dementia.'

Jeremy Hughes, Chief Executive Alzheimer's Society



Examples of poor experiences...



“Very distressing”

“Agitation”

“Environment disturbing”

“Interactions with staff were minimal”

“Often ignored”

“Did not know what was happening”

“Uncertainty about their future”

“Negative feelings”

“Clear exceptions”

(Cowdell, 2010; Porock et al, 2015)



Some areas of intervention have been explored...

For example:

Environmental adaptations (e.g. Waller, 2012)

Training/Education (e.g. Surr et al, 2016)

Specialist wards (e.g. here in Nottingham)

Observation & feedback (e.g. PIE)

Could involving families make a difference?



At home, people with dementia are often supported by family & friends



Who often have personal knowledge of, and close relationships with, the person with dementia



Potential for these relationships and knowledge to improve experiences and outcomes of care for people with dementia



But the limited research available suggests that family carers are rarely involved in the planning or delivery of hospital care...

Research aim...

To explore how **families' personal knowledge** and **expertise** is used and impacts upon **experiences** and **outcomes** of hospital care for people with dementia

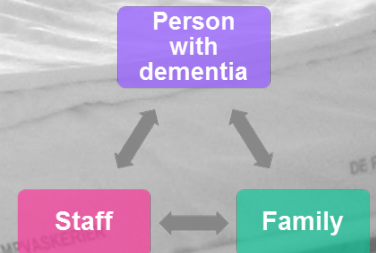
Avoided the limitations of previous studies by:

Including people with dementia

Focusing on general hospital care

Exploring all 3 groups involved

Using an ethnographic approach



Study design...

Data collection

Qualitative, ethnographic approach

Observations, conversations, interviews & documentary data



Sample

Patients with dementia, their relatives/friends, and hospital staff



Setting

Two different elderly care hospital wards

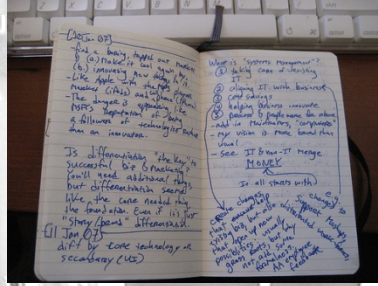


Analysis

Grounded theory approach – data collection and analysis integrated

Data collection...

Observations & conversations



Date: 10/11/11
Time: 11.00-13.00
Location ID: W

Descriptive 'facts':
(Description of participants, physical setting, sensory impressions, events/activities, quotes/questions/actions, interactions (others & mine), etc. perspectives, reactions, responses, effects, emotions/feelings, routines, patterns)
Chronological order:

I decide to go to the ward a little later today to try & coincide with the start of visiting times and to be there during lunch. It is another dizzy grey day but the car park is less busy today and I find a parking space easily.

On arriving at the ward doors I stop to examine the posters on the door that I had failed to note the contents of on my previous visit. There are about six posters stuck to the outside of the double doors covering topics including: The red tabards worn to indicate nurses doing the drug round that shouldn't be disturbed; the ward's zero tolerance policy to abuse and violence; an explanation of the protected meal times policy; a sign informing some staff (I cannot understand the abbreviations used) which buzzer to press; and a poster telling family & friends that the matron is available to discuss their relative's care and they can make an appointment via ward staff. I hadn't paid much attention to the content of these posters previously and so wonder if others do, but when I stop to examine them the overriding feeling is of being told 'the rules' and a focus on 'what not to do'.

I press the buzzer for the ward and am buzzed on by a nursing assistant that I don't know. I explain that I am a researcher and that I was here on Tuesday. I then spot the ward clerk and so explain that she has met me before. The NIA lets me onto the ward and turns to the ward clerk who says 'hi' and 'come in'. I say 'Hi' and sign in, and ask if it is ok to put my bag/coat into the staff room. She says if it has valuable in it to put it behind the desk and hides it in a drawer for me. She says 'You've missed all the action, it was hectic!' I ask why that was and she says there was an MDT meeting this morning. Later a couple of other staff describe the morning as 'busy' and 'mad'.

Behind the desk are all new members of staff that I haven't met before, so I introduce myself to them one at a time when they seem to be less busy. I explain that I am a researcher working with JY and we are interested in what it is like to be in hospital if you have a memory problem such as dementia, and also whether there is anything that we could do to improve experiences of hospital. Most people seem interested and I follow up by explaining that, as I can't interview people, I will be spending time with people with memory problems on the ward and, that as well as being interested in their experiences, I am also interested in the views of family and staff. Several members of staff (QV, Physio and a Sister in particular) then go on to volunteer information about their work and their experiences of working with

Responses to the descriptive 'facts':
(Thoughts, feelings, assumptions, attitudes, ideas, reflections, participant's interactions with me, methods used)

Several times now people have volunteered information about patients with dementia in response to me explaining the study to them. Every time I struggle to recall what they have said as they generally tell me quite a lot of information and I feel that, so I have just met them, I can't get my notepad out to write down what they are saying.

Medical notes



Interviews



77 Care1 Three: When I went in and told him he was not dying. (Yes). He can stop talking like that and he can (hm) sort himself out and it's only him (hm) that's, that's preventing him from going home (hm). And that was it. Overnight he was he was adamant (was he?) that do you know. And he did, he started standing up. He started doing things for himself. (hm) So and because I told him I don't want to be so hands on with him (yes). I don't want to have to help him to the toilet (yes), I don't want to have to help him go for a wee and (yes) do you know that, that aspect of things isn't for my, my eyes to see (laughs)

84 Interviewer: No true is that you know.

85 Care1 Three: It's not. Do you know I'm not a nurse, I'm not a carer (yes) I'm not, I'm just his Granddaughter (yes) and I said that's how I want it to go back to being (yes). I want to be back to being his Granddaughter and his (yes) and his buddy (yes) rather than somebody that's wiping his arse (yes) and er doing everything for him (yes) cos that was awful! And he knew I didn't like doing it (hm) and erm he felt bad for me having to you know (right) having to help him to the toilet. And oh he always, he always apologized and he always said no it don't matter (yes), it's just one of those things! (Yes) if we have to wait for the nurse then you, we might, I might as well help you and do what I can. So we, we got on with it and we never spoke about it again! (Both laugh)

93 Interviewer: Oh dear!

94 Care1 Three: And that's it. So I can take the visions and then (yes) take them out.

95 Interviewer: And get rid of them! (laughs)

96 Care1 Three: I always said to him I never ever want to find out what an 83 year old's pee pee looks like (both laugh). I really don't!

98 Interviewer: No

99 Care1 Three: So what were the first thing when I, he said he couldn't get out of his bed (hm) and he went I need the toilet so I grabbed his thing and automatically I er picked his (pouse) and put it in and he were like "Oh you've got over your fear of 83 year old pee pees pretty quick didn't you!" Well it were either that or you passed on me (both laugh). So we were twice so he's kept his humour (yes) throughout it all (was he?). It's very dry his sense of humour. (Yes). Do you know you look at

Stories of each hospital stay



Data collection... (i.e. where I hung around)



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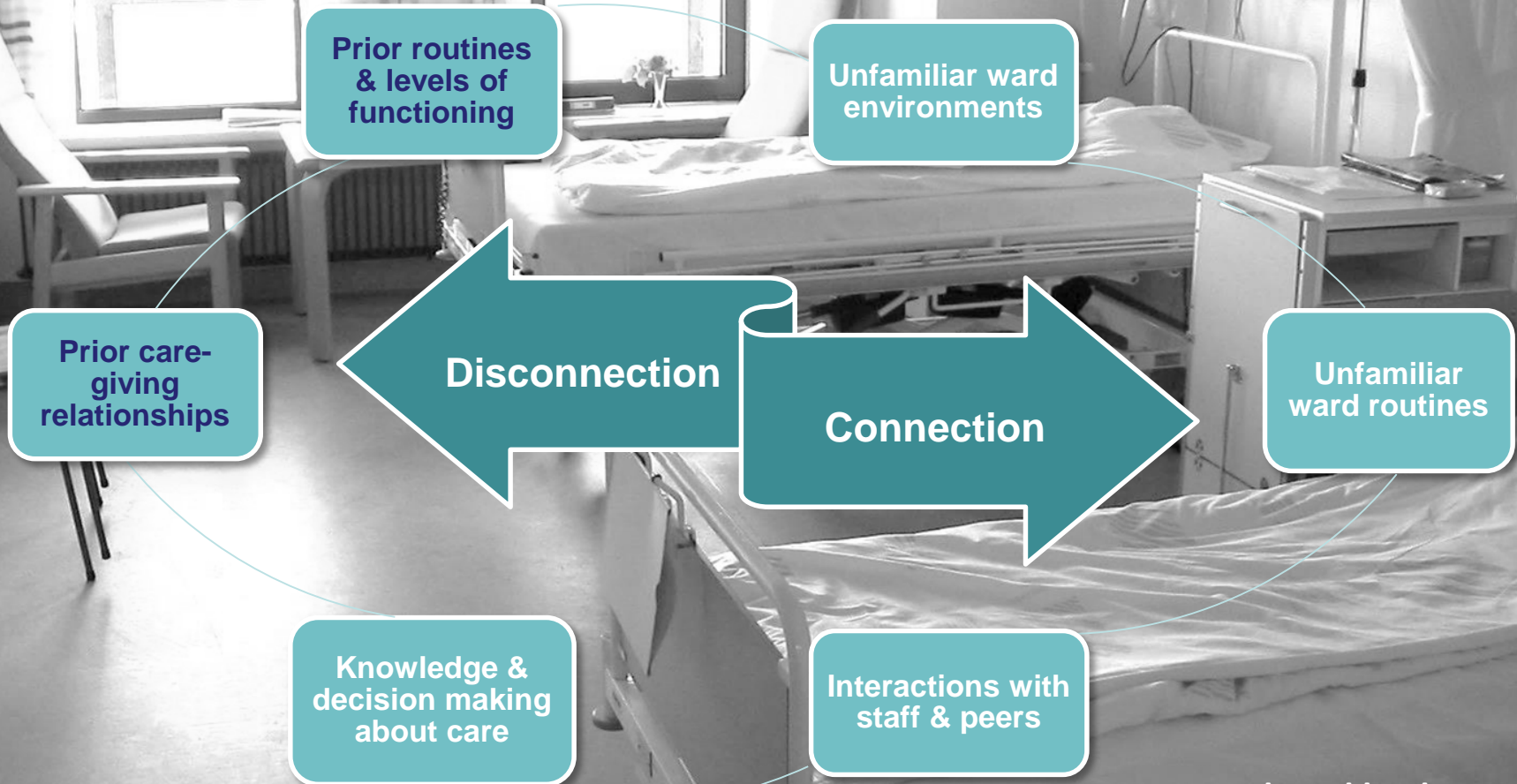


Results...

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Experiences of care...

Multiple ways in which people with dementia were disconnected from or connected with:



Exacerbated by dementia, delirium & physical ill health



Examples of disconnection...

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Examples of disconnection...

From pre-hospital life

Family

Fieldnotes Site 2: Ailsa **cries** a few times during our conversation when she talks about **missing her son and daughter, wailing loudly** at one point when she talks about how much she misses them. Later, when her daughter visits, she says **‘I miss you** anyway, I’ll tell you that. But **I’m forced to do. ‘I miss you and Mark [son]’** she cries, ‘Are you alright, you and Mark?’ sobbing **‘I’d like to come home.’**

Routines

Staff 1: [Speaking about Mavis] “Everything’s **out of her normal routine**, so once she goes home it may be she’s going home **quite different** from how she was.”



Examples of disconnection...

From in-hospital life

Environment

Fieldnotes Site 1: Ailsa repeatedly looks around the dayroom from side to side with an alarmed expression on her face, as if she is unsure or frightened of her surroundings. She says tearfully 'I'm not stupid but where am I? I just can't see where I am.' She asks repeatedly 'Am I alright here?'

Staff

Staff 7: "There's no engagement because there isn't the time because there isn't the staffing for it."

Fellow patients

Staff 12: "They always look lonely because they're not talking to each other."

A grayscale photograph of a hospital room. In the foreground, a hospital bed with white linens is visible. In the background, there is a desk with a chair, a window with blinds, and medical equipment like a lamp and IV stand. The room is brightly lit, likely from the window.

Examples of disconnection...

From in-hospital life

Knowledge & decision making

Joan tells me that her daughter is going to a meeting this week to decide where she is going to go, as if she may be going into care. I ask if anyone has asked Joan where she wants to go and she says 'no'. **She isn't invited to the meeting.**



The effects of disconnection...

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The effects of disconnection...

On emotional well-being...

Fieldnotes Site 1: James is in the dining room, a staff member is sat at the same table. She isn't talking to him, she is looking down at her handover sheet and writing things on it. **'No one likes me, especially not you'** says James. The staff member stares away around the room and **doesn't say anything**. James **says a few more things** – each time the staff member **says nothing** and **doesn't acknowledge him speaking**. She sits still, staring ahead, and gives a big **yawn**. James fiddles with something on his jumper, pulling at it with his hands and asking what it is. 'It's just the pattern on your jumper!' she exclaims, sounding exasperated. James says several more things which the staff member **ignores**, then she gets up and **leaves the room**, leaving James **sat alone**. After she has gone James comments to himself that he is **'useless'** **'I'm sorry'** and **'I want to be dead'**.

A grayscale photograph of a hospital room. In the foreground, a hospital bed with white linens is visible. To the left, there is a white chair and a small table. In the background, there are medical monitors and equipment on a stand. The room is brightly lit, likely from a window out of frame.

The effects of disconnection...

On emotional well-being...

Carer 25: “It [making a connection] would have made a difference to me because then my mum wouldn’t have been as **agitated** as she was, she wouldn’t have been as **upset**, she wouldn’t have been as **frightened**.”



The effects of disconnection...

On care & physical well-being...

Staff 33: “A patient may come into hospital that’s got dementia, that won’t take tablets for you, will become quite agitated if you try to wash them or toilet them. And **you don’t know anything about that person to try and put them at ease.**”

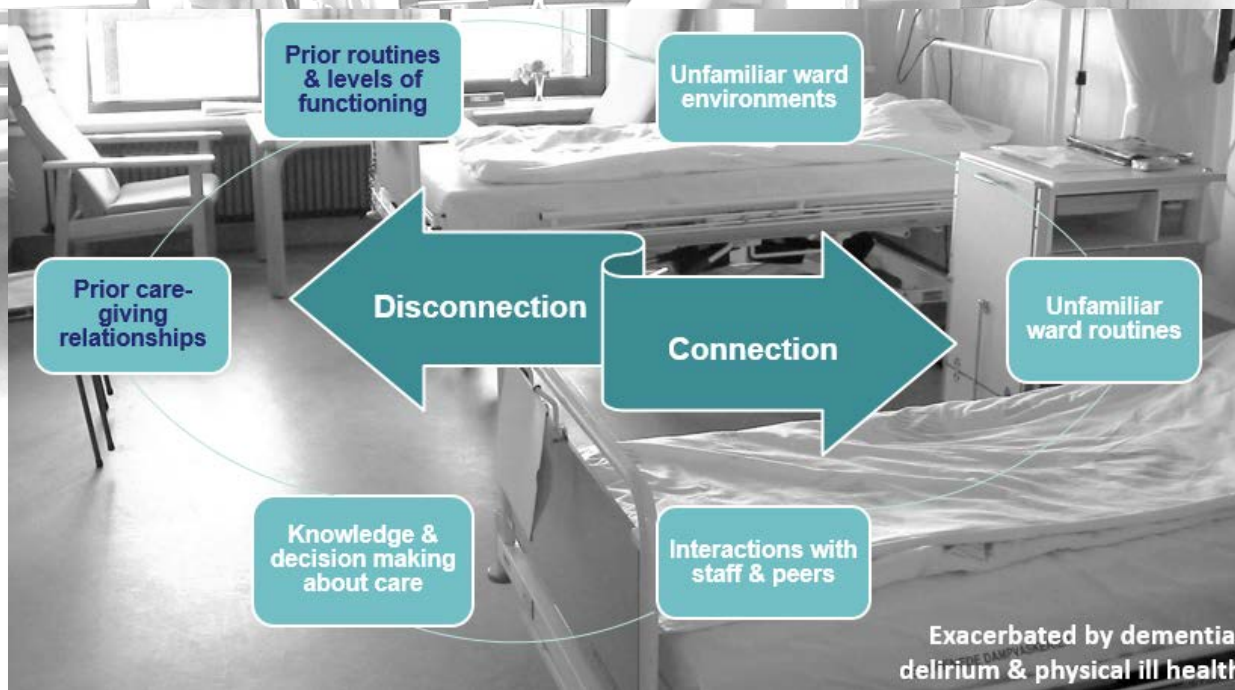
Staff 7: “When you don’t have the staff you can’t do that [engage with people with dementia] and therefore they become a falls, more of a **falls risk**, and also they get **agitated** because you’re **constantly telling them to go and sit back down**, and they don’t want to go and sit back down.”

A bright, clean hospital room with two beds, a desk, and large windows. The room is well-lit, with natural light coming from the windows. The beds are neatly made with white linens. There is a desk with a chair and a lamp. Medical equipment is visible, including a stand with a light and a cabinet. The overall atmosphere is clean and professional.

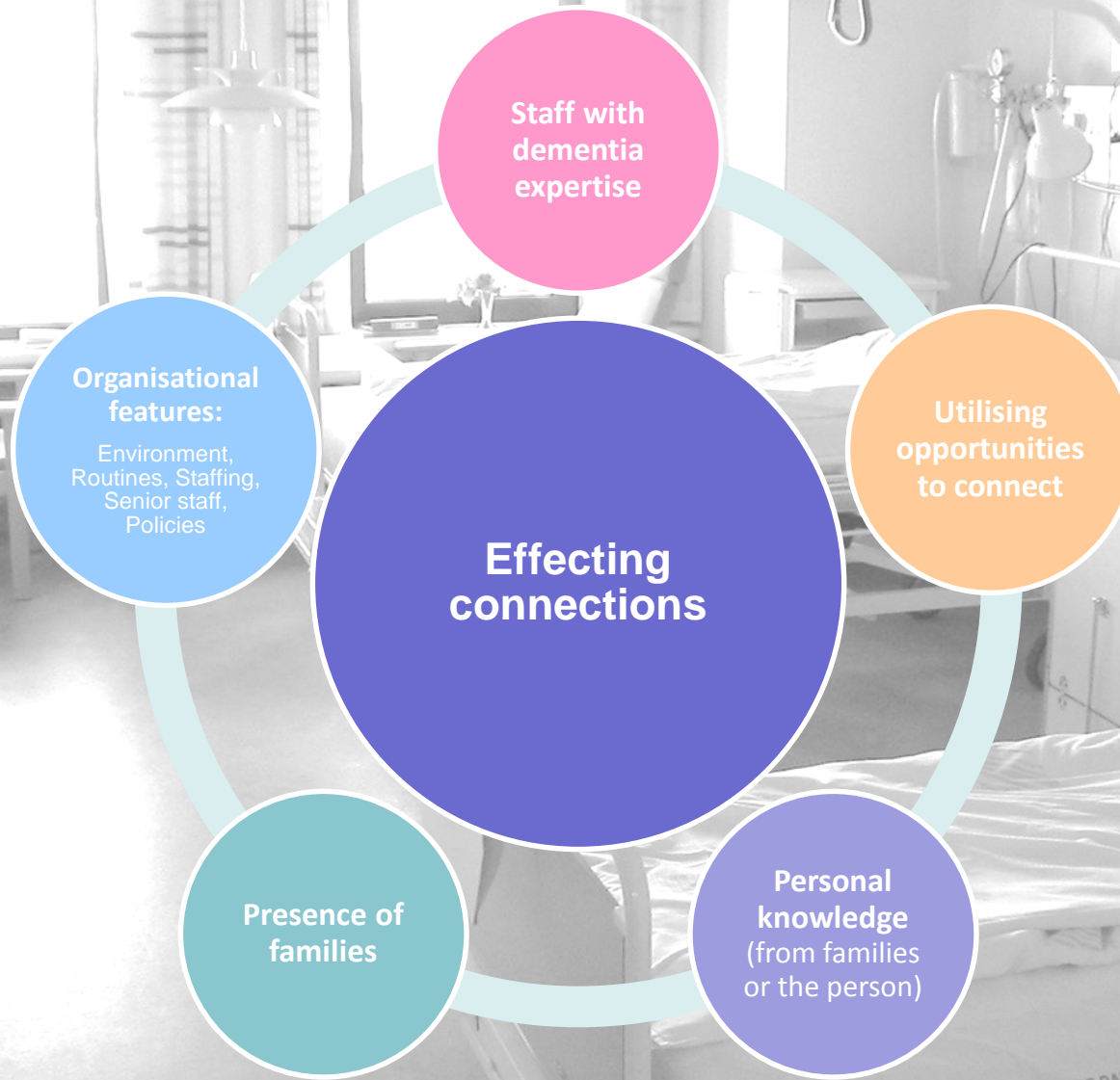
But it's not all negative...

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Creating connections...



Creating connections...





Staff using opportunities to connect...

Staff 9: “One patient, she’d got a bit of dementia... and she was sat in the dining room on her own eating, and so I thought ‘Oh!’ So I went and **sat with her and had my break.** I had something to eat with her and she were, **we were both chatting away.**”

Staff 29: “Usually **when we wash people,** cos you have at least **10 minutes to, well 15 minutes,** and you say ‘Oh, were you ever married then? How many children have you got?’ ...sometimes they can’t remember, but most of them they can... they will just talk and talk... I think **if you didn’t ask they wouldn’t initiate, but I do ask.**”

Families helping staff to create connections...

Personal knowledge from families
facilitating interaction

Staff 32: “It’s like when you’re doing something quite intimate like helping them to have a wash or something, and it’s awful cos **you become a bit detached because you don’t know them**. But then once you see a photo or you speak to the family about what they used to do, then sometimes you can talk to them about that because they can talk about things from the past. So you can say to them “**Oh I heard you used to work at the mills**” and then you’ll find, then they’ll go, we’ll be talking about the mill then for half an hour, and then you feel like you’ve **made a connection** because when you’re doing that **you can see the delight, emotion** or whatever in them.”

A photograph of a hospital room. In the foreground, there is a bed with white linens. To the left, a white chair is visible. In the background, there is a desk with a lamp and some medical equipment. The room is brightly lit, likely from a window on the left. The overall tone is clinical and clean.

Families helping staff to create connections...

Facilitating understanding & communication

A Ward Sister tells me about a man with dementia who **struggles to speak**. She tells me how she **knows what he means**, using examples such as when he **points to the door** he is **asking when his wife is coming**, and when he **points to his chest** he means **he wants a tissue**. A nearby staff member says she wouldn't have known that.

Families helping staff to create connections...

Creating more personalised routines

Staff 12: “...they’ll [family] say, you know, ‘My dad likes to get up at this time.’ ‘They like, they prefer this.’ And I think that’s really helpful... If they [staff] know what somebody’s routine is, what they normally do, then we shouldn’t have as many problems... It’s those **little things** that **help their patient experience**, and they **settle down more** if they’re in that routine.”

Helping to improve care

Staff 10: “If you’ve liaised with the family... they might say ‘well actually when they do this at home it’s because they need the toilet’... it’s just **simple things** like that isn’t it?”

Direct involvement from families helping to...

Identify care needs

Carer 2: “There’s always a **build up to these infections**, it just doesn’t happen overnight. He’ll start getting more **agitated** or he’ll **stop eating** or he’ll **start swearing** a lot at my mum and so **we know it’s building up...** now that he can’t do much I can’t say ‘well he’s no longer doing this and he’s no longer doing that’ because he can do very little for himself anyway... **You can tell though when something’s amiss.**”

Meet care needs

Staff 7: [speaking of a therapy session involving John’s son] “His son just chatted with him if that makes sense... According to the son he knew the football stadium... And his son was trying to **encourage** him to kind of **sit up** and look out of the window that way and **keep his dad’s interest** really in what we were doing... And with that encouragement John was a lot **happier** and he was **smiling**. He seemed a lot **less distressed**. He wasn’t **clinging on to things** or **on to people**. He was actually **following instructions better** from us.”

A grayscale photograph of a hospital room. In the foreground, a hospital bed is partially visible, with white linens. In the middle ground, another hospital bed is fully visible, also with white linens. To the left of the middle bed is a desk with a chair. In the background, there are two large windows with blinds, and a desk with a chair. Medical equipment, including a stand with a lamp and various monitors, is visible on the right side of the room. The floor is a light-colored, polished surface. The overall atmosphere is clean and clinical.

So, was family involvement the norm?

Family involvement was very variable and far from routine...

Varied between and within wards

Staff 32: "It's their relative, and they're vulnerable because they've got dementia, so **locking them** [relatives] **out** and saying **you can't come in** until 2 o'clock, what does that say?"

Fieldnotes: A staff member talks about a consultant on another ward who **refuses** to meet with families.

Families' roles are unclear

Carer 1: "You **don't know** what you're supposed to do, or what their thing is, I mean you don't want to be interfering with them."

Can conflict with hospital policies

Fieldnotes Site 2: The ward sister tells me that they **reduced visiting hours to reduce infection**.

Situation dependant

Carer 3: "I'm **not allowed** to be there when he eats his dinner!"

Staff 22: "You have a two hour span where every relative wants to speak to you and it's not always easy, so you have to **prioritise**."

Involvement in knowledge exchange and decision making could be especially problematic...

Not knowing how a relative was

Carer 20: “When my dad’s in hospital all the time and he’s taken out of his bed and into a chair, **we don’t really see what he’s capable of... we don’t really know** how much **help he needs... they never explained** as to what he can do.”

Not always being involved in decision making

Carer 21: “**We weren’t told about it** [care planning meeting]. I think it was their noticeboard and I saw ‘JCM’ and I thought ‘What’s that?’ so I asked someone at the nurses station and they said ‘Oh it’s a meeting we’re having on Wednesday, you’re invited if you want to come.’ ”

Carer 2: [who provides daily care for his dad] “The homecare staff told mum he was coming home on the 23rd and I **knew nothing about it... No one told me anything.**”

And family involvement was not uniformly beneficial...

For example, in decision making...

Family wishes are often talked about in MDT discussions but the wishes of the person with dementia are often not known or not talked about:

Fieldnotes Site 1: MDT discussion around a lady with dementia: Someone says 'daughter raised several concerns about managing at home'. 'Daughter thinking about placement then?' someone else asks... 'Sounds like need to speak to her (*daughter*), see what she wants'.

There is no mention of what the lady wants.

Attention to involving people with dementia and to understanding their needs and wishes is also required



Impacts on outcomes...

Difficulty in making decisions

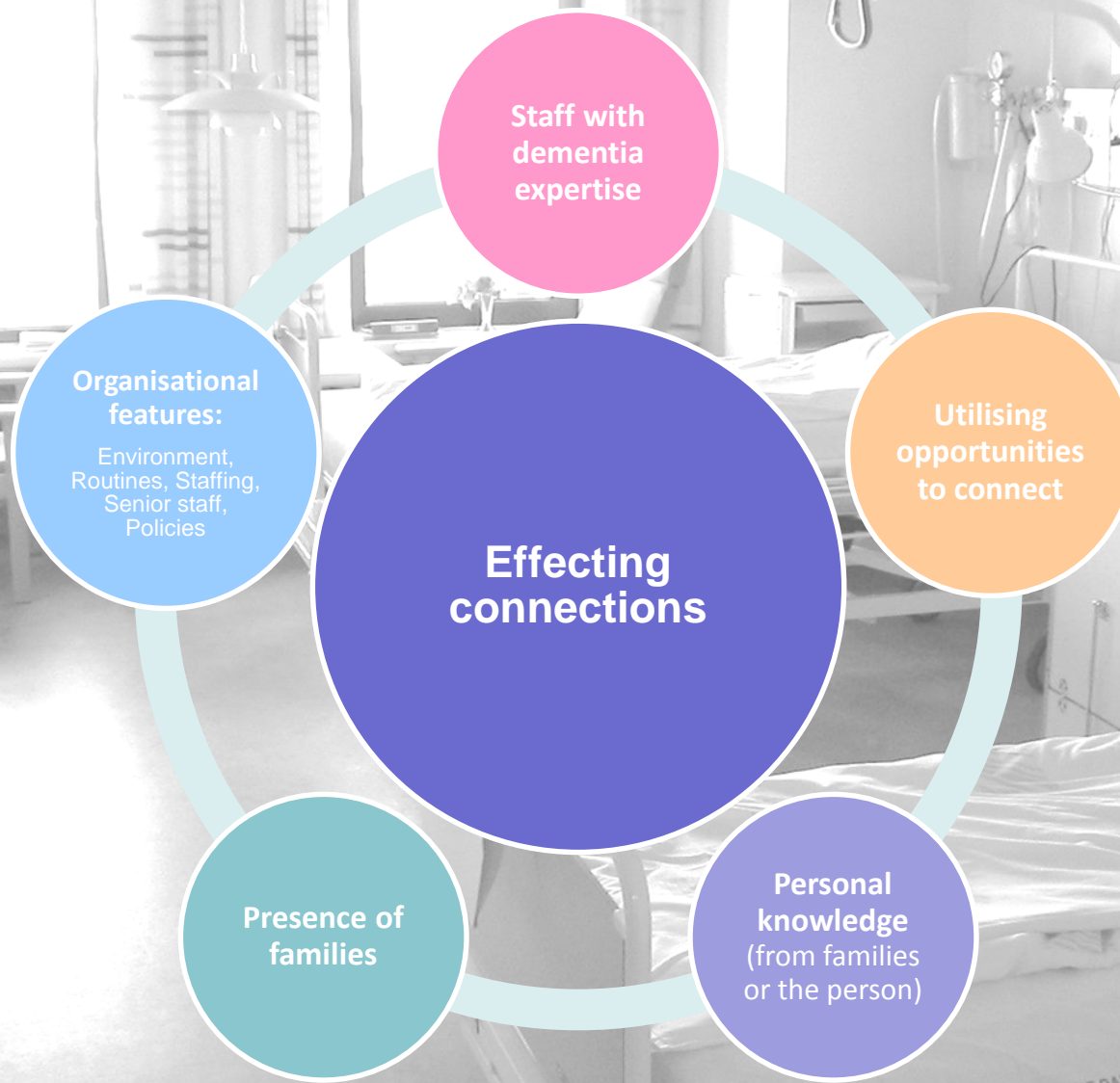
Delayed discharges

Decisions which did not accord with the person's needs or wishes

Potentially irreversible deterioration

Stress for the person & their family

Implications for practice...



Implications...

For improving hospital care...

John's Campaign

for the right to stay with people with dementia

for the right of people with dementia to be supported by their family carers

STAY WITH ME

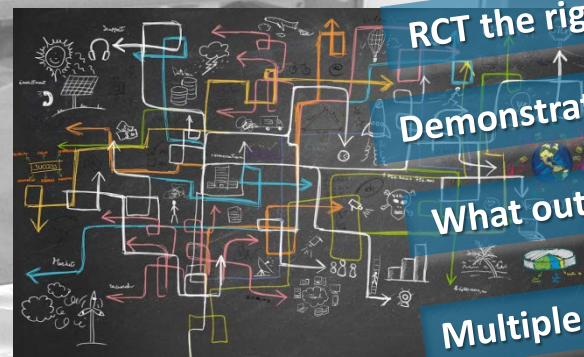
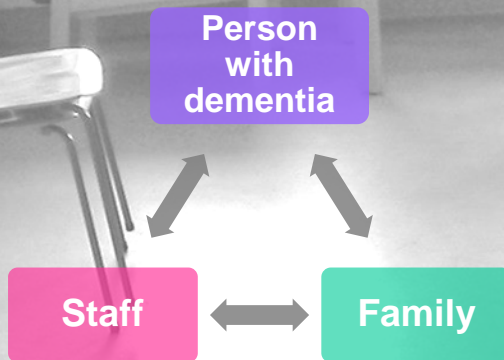
Informing current family involvement initiatives

Developing guidance for involving families in care

- **Clearer guidance** that takes the complexities of involving families into account and provides practical approaches
- Ways of **ensuring people with dementia are not overlooked**
- Overcoming potential barriers such as **staffing, environment, conflicting policies, culture**
- Support & modelling from **senior staff**
- Encouraging staff to **utilise opportunities** to connect with people with dementia and with their families
- **Training & staff with dementia expertise**
- **Paperwork** which makes it easy to collect & use families knowledge
- Clearer messages about families **access, welcome** and potential **roles**

Implications...

For future research...



RCT the right approach?

Demonstrating an effect?

What outcomes?

Multiple components

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A grayscale photograph of a hospital room. In the foreground, a hospital bed with white linens is visible. To the left, there is a desk with a chair. In the background, another bed and a window with blinds are visible. The room is brightly lit, likely from the window. The text is overlaid on a semi-transparent white box in the center of the image.

Thank you for listening.

Please feel free to ask any questions!

Or if you think of any questions later, or want to get in touch,
please do:

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