Promoting excellence in hospital care for people with dementia: a UK case study

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Background

- **People with dementia over 65 use up to \( \frac{1}{4} \) of UK hospital beds**, and are staying for longer than other people who go in for the same procedure. This is putting a resource strain on an already struggling health system (Alzheimer’s Society, 2009).

- Instances of **poor care** and inconsistent assessment, information sharing, planning and delivery of personalised care in hospitals have also been identified (The Care Quality Commission, 2014).

- **Areas that require improvement** have been identified including: assessment for delirium, communication of relevant information at discharge, recording of information pertinent to people’s care and dementia awareness training at staff inductions (Royal College of Psychiatrists, 2013).
• Carers, families and friends of people with dementia have reported concerns too.

• In a Facebook survey in 2015, out of 570 respondents:
  • only 2% said that, in their experience, all hospital staff understood the specific needs of people with dementia;
  • 57% said they felt the person they care for was not treated with understanding and dignity in hospital;
  • 90% said they felt the person with dementia became more confused while in hospital;
  • 92% thought hospital environments were frightening for the person with dementia.

• The survey also revealed instances of people with dementia being treated with excessive force, of poor catheterisation leading to a urinary tract infection, of visits from family members and carers being denied, and of people not being changed or cleaned up after being incontinent.

(Alzheimer’s Society, 2016).
Aims

• To improve outcomes for people with dementia while in hospital in a Southern region of UK, the funder has been working with eight acute hospitals on an Acute Care Development Programme (ACDP).

• ACDP set out to identify, spread and share good practice of dementia care in hospitals, determine what practices or interventions were making the greatest impact and assess their impact.

• Each hospital was engaged in a range of improvement interventions and we undertook an evaluation that examined:
  – whether and how the programme made a difference to people with dementia and their family members in the participating hospitals;
  – staff views and experiences of setting up and working with the interventions.

• The aim was to share the successes and challenges across the region and beyond.
What we did

• One researcher spent two days in each hospital.

• Mixed methods
  – Unstructured observations of interventions
  – Semi structured interviews with people with dementia
  – Focus groups with staff and volunteers
  – Participant diaries

• Using various methods allowed different types of information to be gathered about the hospital wards and interventions and for a deeper understanding of each.

• Inductive thematic analysis managed in Nvivo10.
• **Improvement interventions** included: visiting musicians, volunteer befrienders, open visiting, staff awareness of dementia and identifying dementia champions.

• Each hospital was delivering (or planning to deliver in the near future) between five and eight improvement interventions.

• We **planned to evaluate the interventions as they were happening** on the wards during our two day visit.

• However, this was **not always possible** as the interventions were not running on the days of our visit, or they were not yet running as ward staff were waiting for approval from hospital managers or Boards of Directors.

• This did significantly **limit the amount of time we were able to spend observing interventions** happening.
Participants

- 11 interviews (8 single interviews; 3 dyad interviews with family carers)
  - 6 focus groups with staff and volunteers

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<thead>
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<th>People with dementia</th>
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<th>Staff</th>
<th>Volunteers</th>
<th>TOTAL</th>
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1. Feeling valued and recognised as a carer

- Family carers appreciate extended visiting time so they could stay at the hospital for longer, and being encouraged by staff to help with their relative’s care:

Yeah. It is important to me, ‘cause I like to be with her and she likes me to be here. Although sometimes she’s asleep a long time, but I’m here for her and I’m...you know, rather than sit at home and worrying... what’s happening, how is she, I’m here and, you know...and I’m on hand. (GCM1)

2. Making a difference for the person with dementia

- Family carers value seeing their relatives participate in activities, smiling and enjoying themselves whilst in hospital, and having someone (staff or volunteer) spending time talking to the person with dementia whilst they are in hospital:

...... relatives appreciates it so much.... They really like to think that there is somebody with their loved one when they're not there and it does make a big difference. (GVM1)
Benefits to people with dementia

1. Uphold personhood
   • Interventions (such as Memory boxes) can potentially promote a person-centred approach to practice; in which the individual is recognized and respected and their abilities and preferences are supported.
   • The day room was described by a person with dementia as relaxing and providing an opportunity to meet other people with dementia:
     *Oh, I like it in there, it’s relaxing... Nice cup of tea. The folks in there are much in the same boat as yourself... so there’s a bond there immediately because you know...you understand each other. You don’t have to talk about it but you know it.* (FPM1)

2. Facilitate reminiscence
   • Staff spoke of the value of activities and music for stimulating conversations and facilitating reminiscence:
     *... and the music activity again is quite similar because you’re getting all kinds of levels of interaction from the bedbound, who suddenly start singing.* (FSF3)
   • One participant with dementia reminisced about his own time as a musician following an enjoyable session with the hospital musician:
     *I played the clarinet extensively and I had the opportunity to play in two...the 1914 war.* (APM1)
Benefits to staff

1. Helped to identify the person as having dementia
   - Different hospitals used different methods to signal to staff that a person has dementia (coloured plates or trays, stickers above the bed):
     ... it [butterfly sticker] reiterates the importance of, actually, when you’re looking after somebody with dementia. And, it’s quite discrete, that’s what I like about the Butterfly Scheme, it’s not in your face, you know, it’s not, like, an I’m allergic band, it’s something that’s quite discrete and quite subtle. (DSF1)

2. Helped to manage complexities of caring
   - Staff spoke of some of the complexities of caring for people with dementia who may feel unsettled in hospital, and the benefits of having volunteers sitting and talking to them:
     ... it’s great that they (volunteers) sit and chat with patients (ASF1)

3. Formalised care practices
   - Interventions were seen by some staff as a formalization of good or innovative practice already carried out and having the potential to promote consistency of practice and therefore the experience for people with dementia and their families across the hospital:
     .... So I think we were halfway there but we didn't really realise it, well probably 90 per cent there but didn't really realise it. So we’ve just made it a bit more official. (ASF2)
1. **Time to talk**

There were many accounts of volunteers’ experiences of working in creative ways with people with dementia, from engaging in craft work, to reminiscing with scrap books or memory boxes, to spending time sitting or talking with them.

*But we play cards, we do colouring, we do all sorts. It's lovely.* (HVF1)

2. **Opportunity to give something back**

Volunteers spoke of the benefits to them of the work they do to support people with dementia in the wards, and of the impact of their work on family members.

*I think volunteers get a lot out of it as well to be honest with you.* (GVM2)

*I find it very rewarding because I get people who probably haven’t spoken to anybody for a very long time.* (HVF1)
1. **Securing funding**

- Issues of cost or lack of funding was reported widely across the hospitals as being a challenge or barrier to implementing interventions.
- The constraints of funding meant that some interventions were only partially implemented, not continued or delayed.
- However, staff are very committed to fundraising and seek local support for meeting costs of valued interventions.

*No, the coloured plate scheme was going ahead but, actually, due to costings again, and coming out of ward budgets, it wasn’t unfortunately taken forward.* (DSF1)

2. **Lack of equity in access to interventions**

- Interventions do not appear to operate consistently across Trusts. Even within hospitals, there seemed to be a difference between wards in their implementation or knowledge of particular interventions.

*It would be nice if every ward had the same.* (GSF5)
3. **Lack of awareness of interventions**

- An inequity in access to interventions stemmed from lack of awareness that it exists, or its purpose.
- Lack of awareness of an intervention within a hospital can lead to incorrect information being given to family members:

  *I didn’t realise it was open visiting, I was told it was two until three and seven until eight. So, is it open visiting? (DCF2)*

4. **Insufficient training and understanding**

- Some staff had concerns over the level of training and support volunteers received:

  *we’ve had a complaint from one of them (volunteer) because they didn't want to sit with alcoholic patients as they didn't think that was part of their job. We’ve said to them they might not have dementia they’ve got massive cognitive impairment... but they didn't like our kind of patients. (ASF5)*

- Some staff were concerned about the potential indiscriminate use of interventions (such as Twiddlemitts), without considering its utility, appropriateness or value for people with dementia.
5. Levels of support to effect change

- Different levels of support throughout the hospital are necessary to effect change – implementing interventions without management support is difficult.
- The value of having Dementia Champions to help take interventions forward was also raised as an important facilitator for change:

*I will certainly be able to feed through the idea then, so all the champions; there should be somebody on each ward who can then take it forwards.* (FSF2)

6. When and where to run interventions

- Finding appropriate space to deliver interventions can be a challenge:

*...the idea was to have so they could stay over, have a bed to sleep in here, that hasn’t materialised though, because that was one of the main...to try and get a camp bed or Z bed. There were some concerns about.... the fire issues, somebody actually sleeping in here, so that’s gone back to the fire officer, which would be nice, because at least if they wanted to stay, they could stay.* (FSF1)
1. **Concern not to over-burden and managing expectations**
   - Staff were concerned that some interventions (such as open visiting) may have an unintended consequence of removing the opportunity for carers to rest or take respite.
   - In reality we found that open visiting did not result in an increase of carers wanting to stay overnight, but did mean that they could support staff with activities such as helping to feed people with dementia at lunch time:
     
     *I mean, we’ve always been quite proactive with allowing relatives to come, we try and promote it, especially for people living with dementia, because actually they’re familiar to them, so we do encourage that. So, we have, sort of, been doing a little be of that anyway, and I think it’s a good thing, to get the relatives to come in.* (DSF3)
   - Others were aware that some relatives of people without a cognitive impairment might use these interventions to enable them to stay with their relative all day.

2. **Flexibility of intervention use**
   - Staff recognised that interventions should not be used generically for all people with dementia. Flexibility of use also relies on knowing the person’s condition and abilities and tailoring an intervention to match these:
     
     *I think, some people do like them [the Twiddlemitts], other people just throw them straight on the floor.* (DSF3)
1. **Insufficient personnel to deliver person-centred care**
   - Insufficient personnel to deliver interventions is a widespread concern: The problem I’ve got with my day room is as soon as I go out to the toilet with someone, someone else can fall, and we had two falls when I first started, and we haven’t had any more since, touch wood, but it’s always the fear that as soon as I turn my back or I need to go and get a wheelchair to get someone else to come in, the people here are unsupervised. (FSF3)

2. **Fragility of relying on volunteers**
   - Staff recognise the fragility of relying on volunteers to deliver an intervention: I’d like to have a bank of three or four, rather than one or two, so it’s the gaps in between, you can’t plan a consistent delivery of service without the second volunteer. (FSF3)

3. **Insufficient management support**
   - This only arose from one hospital and therefore cannot be generalised. However, staff felt that there was a lack of support from management to enable them to take forwards interventions and activities for people with dementia, describing key challenges as: needing to obtain approval from the Board of Directors for new interventions, lack of funding and staff to take them forwards, and resistance from other staff.
Conclusions

- Two key facilitators of successful implementation of interventions: management support and a dedicated Dementia Champion or Dementia Team.

- This relatively small study allowed a snapshot of different types of non-pharmacological interventions to improve the experiences of people with dementia while in acute hospital, and also the experiences of family carers.

- All hospitals used a variety (toolkit) of interventions to meet different needs (for example nutrition, socialisation, comfort and additional support) in ways that had the potential to uphold the personhood of those with dementia.

- Using a ‘toolkit’ approach has the potential to meet the preferences and needs of the heterogeneous population of people with dementia in hospital.

- Such a toolkit could also be rolled out more widely to improve well-being for other groups of people in hospital too.
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