

COMMENTARY

Can person-centred care for people living with dementia be delivered in the acute care setting?

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Abstract

The need to improve care for people living with dementia in the hospital setting has long been recognised. Person-centred care has the potential to improve the experience of care for persons living with dementia and their carers, and has been shown to improve the experiences of hospital staff caring for the persons living with dementia, however it remains challenging to deliver in a time- and task-focussed acute care setting. This commentary suggests that to embed person-centred care across the hospital environment, cultural changes are needed at organisational and ward levels. In particular there needs to be: leadership that supports and advocates for workforce capacity to recognise and meet both psychological and physical needs of people living with dementia, promotion of physical environments that support familiarisation and social interactions, an inclusive approach to carers and the development of a culture of sharing knowledge and information across hierarchies and roles. An evidence-based set of pointers for service change are described which highlight institutional and environmental practices and processes that need to be addressed in order for person-centred care to become part of routine care.

Keywords: dementia, person-centred care, care culture, hospital environment, acute care, older people

Key points

- There is a well-recognised need to improve care for people living with dementia in the hospital setting.
- Embedding person-centred care in the acute care environment requires changes at organisational and ward levels.
- For a whole culture of care change to occur, senior management needs to recognise it and advocate for it.
- A systems wide approach that bridges understanding individual needs with priorities of the acute care environment is needed.

It is been almost 10 years since Tadd *et al.*'s [1] publication of *'From Right Place - Wrong Person, to Right Place - Right Person: Dignified Care for Older People'*, which described the mismatch in care for older adults in hospitals and the organisation of acute care. Even with the best intentions, the care observed was variable, between and within wards, reflecting both the systemic and dynamic natures of the issue. The study highlighted that for older adults with dementia, problems were accentuated further, with staff being unsure how best to care, and people living with dementia being seen as being a 'risk' or disruption which needed to be managed, resulting in practices that were often poor. Despite calls for action to improve care for people with dementia in the

hospital setting in the UK [2], and internationally [3, 4] it appears that caring for those with dementia continues to challenge the acute care system.

The concept of using a person-centred care approach for people living with dementia, pioneered by Tom Kitwood [5], has had a significant impact on the way we approach care for people living with dementia. The goal of person-centred approaches is to respect personhood and in so doing, optimise the quality of life of the person living with dementia despite the consequences of their neurological impairments. Whilst there has been an increased recognition of the importance of a person-centred approach with many staff practicing this on a daily basis, and with the majority

of hospital trusts in England committing to the National Dementia Action Alliance *Dementia Friendly Hospital Charter* [6], the evidence suggests that the context of acute care still challenges the ability to routinely deliver person-centred care.

In our recent set of linked systematic reviews aimed at understanding and improving experiences of care in hospital for people living with dementia, their carers and staff [7], person-centred care was seen to be crucial to decrease the heightened fear and insecurity that persons living with dementia can experience in the hospital setting. We found that whilst staff acknowledged that providing person-centred care was optimal, they often felt prevented from approaching care in this way due to the prioritisation of tasks and routines. Our overall finding was that to improve the experience of care, there needs to be a transformation of organisational and ward cultures that recognises and values the status of dementia care and provides for both psychological needs and physical care. Aspects of hospital culture that need to change include building workforce capacity to meet both psychological and physical needs of people living with dementia, creating physical environments that support familiarisation and social interactions, having an inclusive approach to carers and developing a culture of sharing knowledge and information across hierarchies and roles. Our conclusions were echoed by Røsvik and Rostad [8], whose review of what best meets the needs of people with dementia in hospitals also highlighted a lack of research into models of care that best support the psychosocial needs of people living with dementia.

So how do we implement and embed person-centred care in the acute hospital environment? Can it be done?

Firstly—there is no ‘one size fits all’ model of person-centred care that can be easily implemented. A generic or formulaic approach to person-centred care might even make matters worse. Ethnographic studies of conversations in the acute care setting, where staff through their best intention of being person centred and asking questions such as—is there anything else you want, or need?—can result in the person living with dementia feeling more confused or agitated [9]. Secondly, although education and training in dementia awareness and skills for clinical and non-clinical hospital staff has been established as being critical to improve the quality of dementia care [4, 6], they may not be sufficient on their own. Handley *et al.* [10] in their realist review of dementia friendly environments suggested that in order for there to be changes to care practices, training of staff had to be combined with a recognition and valuing of the staff role itself. Endorsement from senior clinical leaders and management was needed in order that staff felt confident that they had the authority to adapt working practices to meet emerging needs and provide good dementia care.

Alongside this, the importance of a dementia friendly environment on the ward and within the hospital has been recognised [6]. Dementia specialist units within acute care, where the focus of the unit is the person with dementia, that combine many recommended strategies have been suggested

as a potential solution. Such units, which combine medical and mental health expertise, have found that whilst this might not necessarily improve an individual’s health status nor reduce hospital resource use, patient experience and family carer satisfaction can be improved, which for many approaching the end of their lives, might be considered significant outcomes [11, 12]. Germany seems to have taken this approach and recognises the establishment of specialist dementia wards as being one of the measures needed to improve dementia care in hospitals [13]. But is it feasible or realistic for every hospital to have such facilities, especially at sufficient scale to meet the potential need? Perhaps yes, if significant investment is made, and there are sufficient organisational levers in place to support it, such as senior management who advocate for the idea and recognise that a change to the whole culture of care is required and is possible.

We know that standardised approaches to care, such as time-based targets or routinised task focussed inpatient care, disadvantage patients with needs that do not fit the prescribed approach [14]. Organisational preoccupations with risk aversion, restrict patient choice and person-centeredness. There is a tension between the drive to limit the time spent in a hospital against spending time to understand the patient and fitting in around their needs, though our reviews suggested that if more time was spent on getting to know the person living with dementia, time could be saved across many areas of care⁷, and it can improve the experiences of hospital staff caring for persons living with dementia [15]. We need to start unravelling a system that has been increasingly based on such targets and standardised processes, and until we are able to do that, we need to make changes where we can. Working with the clinical and patient members of the wider project team in our review, and drawing from the evidence in the studies, we developed a set of pointers for service change which highlight institutional and environmental practices and processes that need to be addressed to improve the experience of care in hospital for people living with dementia, their carers and those caring for them [7]. They cover areas of: Dementia awareness and understanding, Education and training, Modelling of person-centred care by clinical leaders, adapting the Environment, teamwork (Not being alone), taking the Time to ‘get to know’, Information sharing, Access to necessary resources, Communication, involving family (Ask family), Raising the profile of dementia care, and Engaging volunteers, spelling out the acronym DEMENTIA CARE. The details within each pointer are shown in Figure 1. The pointers emphasise the importance of dementia care being a hospital wide approach, not something that is restricted to the ward. All areas of the hospital, from reception, to out-patient clinics to emergency departments need to take a person-centred care approach. Such changes would likely be of benefit to everyone—not just persons living with dementia. Figure 2 depicts this in the visual representation resource we created, available as a booklet at <https://arc-swp.nihr.ac.uk/research/projects/caring-about-care/>, with the extract here showing ‘M’- Modelling of person-centred care by clinical leaders.

Caring for people living with dementia in the hospital setting

D ementia Understanding	Increase awareness and understanding amongst all hospital staff that responsive behaviours are most likely a communication of unmet needs	C ommunication	Reintroduce oneself, remind (who, where, why) and reassure
	Recognise that people living with dementia cannot always communicate their needs, and may be disorientated, thirsty or in pain		Involve carers early in discharge planning; beneficial for the person living with dementia and helps reduce carer anxiety
E ducation and training	Make basic dementia training part of routine induction training for all clinical and non-clinical staff	A sk Family	Extend visiting hours for family and carers to help improve the experience of care for all
	Provide advanced training for staff working on older adult wards, to further their understanding of dementia and give confidence in delivering care		Involve family and carers in decisions about care and keep family informed
M odelling of PCC from leadership down	Explore ward-based options for training, including staff across disciplines	R aise the profile of dementia care	Invite family who are interested in helping to be involved in assisting with care practices (e.g. help with eating, drinking, washing)
	Encourage senior staff to demonstrate their belief in and understanding of the importance of valuing psychological health of people living with dementia as this will encourage others to do likewise		Prioritise dementia care
E nvironment	Undertake a 'Dementia-friendly' environment review and involve people living with dementia, carers and staff (from a variety of roles) in the review	E ngage Volunteers	Motivate and reward staff to undertake roles and training that champion dementia care
	Avoid moving people living with dementia where possible and orientate often e.g. clocks, newspapers, signage		Explore volunteer opportunities with local agencies
N ot alone	Organise staff rotas to maximise familiarity and consistency for people living with dementia	T ime	Consider having a formal volunteer strategy to maximise the volunteer potential
	Encourage personalisation of the space around people living with dementia e.g. with photos, favourite throw or blanket		Manage staff and volunteer expectations regarding the presence and role of volunteers on the ward
I nformation sharing	Help staff to know they are not alone and support strategies for self-care	A ccess to resources	
	Create ward cultures that supports staff and encourages them to look after themselves as this will benefit staff and people living with dementia		
T ime	Spend time getting to know people living with dementia. This will save time across many areas of care		
	Make space to document psychological wellbeing and/or distress		
I nformation sharing	Use simple systems to identify whether someone has dementia: this can help remind everyone to take more time with care		
	Share personal likes and dislikes, and individual behaviours e.g. preferred name, family situation		
A ccess to resources	Tailor activities to the individual to help reduce responsive behaviours		
	Provide access to simple and inexpensive activity resources such as playing cards, newspapers and magazines, as these are easy to replace when thinking about infection control		
	Explore opportunities to access specialist advice		

Figure 1. The DEMENTIA CARE pointers for service change highlighting institutional and environmental practices and processes that need to be addressed to help embed person centred care in the acute hospital setting.

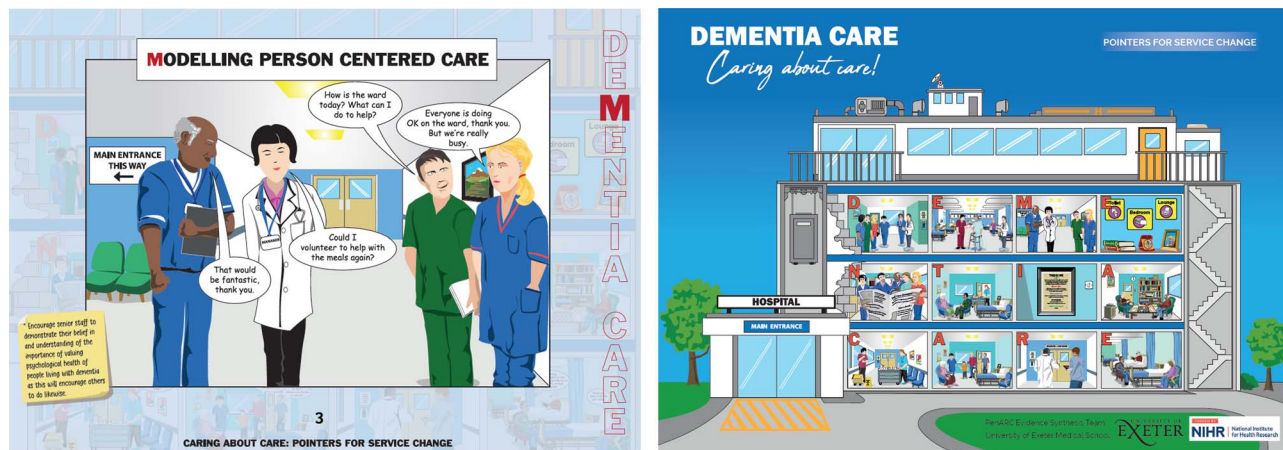


Figure 2. Extract from the Pointers for Service Change booklet on how to improve the experience of care for persons living with dementia in the hospital setting – showcasing ‘Modelling person-centred care’.

Hospitalisation for an older adult with dementia remains very challenging. The environment is unfamiliar, routines are disrupted, and for many, their needs remain unrecognised or unmet. Furthermore, many may have superimposed delirium. Working out how best to improve their experience of care will take a systems wide approach that can bridge understanding the needs of the individual with the priorities of the acute care environment.

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