

ORCA - Online Research @ Cardiff

This is an Open Access document downloaded from ORCA, Cardiff University's institutional repository:https://orca.cardiff.ac.uk/id/eprint/132212/

This is the author's version of a work that was submitted to / accepted for publication.

Citation for final published version:

Featherstone, Katie, Boddington, Paula and Northcott, Andy 2020. Using signs and symbols to identify hospital patients with a dementia diagnosis: help or hindrance to recognition and care? Narrative Inquiry in Bioethics 10 (1), pp. 49-61. 10.1353/nib.2020.0026

Publishers page: http://dx.doi.org/10.1353/nib.2020.0026

Please note:

Changes made as a result of publishing processes such as copy-editing, formatting and page numbers may not be reflected in this version. For the definitive version of this publication, please refer to the published source. You are advised to consult the publisher's version if you wish to cite this paper.

This version is being made available in accordance with publisher policies. See http://orca.cf.ac.uk/policies.html for usage policies. Copyright and moral rights for publications made available in ORCA are retained by the copyright holders.



1

2

- 3 Using signs and symbols to identify hospital patients with a dementia
- 4 diagnosis: help or hindrance to recognition and care?

5

6

Introduction

7 There are concerns that care needs of people living with dementia on hospital wards are 8 not being fully recognised. This patient group may have particular difficulties in 9 communicating their needs and wishes, yet it may not be straightforward for staff to 10 determine which patients on a ward have an additional dementia diagnosis, and thus 11 may require particular care, attention, and support. In response, various local and 12 national schemes have been introduced that use signs and symbols to indicate to 13 hospital staff which patients on an acute ward are also living with a diagnosis of 14 dementia, with the aim of improving care for this group. This paper draws upon 15 ethnographic work across five hospital sites in England and Wales, that raises serious 16 questions about the efficiacy and appropriateness of such signs and symbols, and 17 concludes that in some respects, signs and symbols indicating a dementia diagnosis 18 may even introduce additional obstacles to high quality care. This raises issues about 19 how best to facilitate good communication between patient and carers, and how to

achieve the ethical imperative of ensuring that patients are recognised and their needsvisible.

Objectives and background

The importance of attention and of 'seeing' the patient

This paper examines the ways in which people living with dementia are perceived and recognised during their admission within an acute hospital ward and how this affects the provision of their care. We consider the impacts of a number of signs and symbols intended to assist with the recognition of patients and their needs. Philosophical and biomedical perspectives agree that how someone is perceived is critical to their wellbeing. It is a truism that a person's needs and wishes must be recognised in order for others to respond to them. How one is seen affects self-perception and empirical studies suggest that this impacts on physical functioning and independence, clinical outcomes, recovery from disability, longevity, and the 'will to live' (Levy, 2009). This may be particularly important for older people and people living with dementia, who constitute significant populations within acute wards.

Attention to the world around us can take different forms. One such form may be narrow, task-based attention, focusing on an object or objects, often for the purposes of goal-directed behaviour. Another, wider-focused attention may be characterised by a receptivity or a listening to the world (McGilchrist 2009). These forms of attention may both complement and compete with each other. Some philosophers stress the importance of a broad and receptive attention to the world and to the individuals we

encounter as critical for ethics (Heidegger, 1996; Weil, 1952) and even that openness to others is a precondition for individual consciousness (Thomson, 2001).

Appropriate action requires attention to the morally relevant features of our world. Compare two approaches to moral knowledge. In an approach common in modern analytical moral philosophy, we owe respect to persons, understood as beings who possess reason, a conception of themselves as continuing over time, and desires including those for their own future; who are capable of reciprocal recognition and interaction with other persons. Hence, we may need to acknowledge explicitly another *qua* person in order to act appropriately to their moral standing (Tooley 2010). On another approach, more characteristic of phenomenology, we may recognise the moral standing of another more directly; our attention to them simply reveals to us that here is someone with certain claims upon us (MacNaughton 1988).

In parallel, there has been a significant focus on examining the intersections of biomedical technologies with medical knowledge and practice, particularly on ways of seeing and the processes of diagnosis and classification. These emphasise, for example, the ways in which technologies provide different ways of seeing and bringing a condition into being (Mol, 2002), how clinical staff apply knowledge and classificatory systems determined elsewhere (Berg 1992) and the emergence of new forms of knowledge that are no longer established exclusively in the biological or the clinical realm. However, the everyday technological, the materially modest technology of the signs and symbols introduced at the bedside to aid recognition of a diagnosis of dementia that have become embedded within the routines and organisations of wards,

has received little attention. Here we examine their role in shaping the mundane and everyday routine care older people receive at the bedside, day in and day out during an admission.

Our focus is the care of people living with dementia during their admission within the acute hospital ward, a setting that admits a general adult patient population. Although there is a small body of ethnography that explores the experiences and care older people receive in acute settings (c.f. Cowdell 2010), few studies have focused on people living with dementia (Norman 2006 and Tadd et al 2011, 2012, Prato et al 2018). Norman's observation of wards within one general hospital found that people living with dementia were viewed by the healthcare professionals as either 'positive and acceptable patients' or 'negative and unacceptable patients' (2006:458). Similarly, Tadd et al's ethnography identified ageist attitudes amongst ward staff as a feature of ward cultures that failed to provide dignified care (2011).

Hospitals, nursing and seeing the person

A key development in the contemporary acute hospital ward is the increasing number of admissions of older people living with dementia, or other cognitive impairment. It is estimated that up to half of all acute hospital beds in the UK are currently occupied by someone with both an acute condition and also living with dementia (Mukadam and Sampson, 2011; Alzheimer's Society 2016). People living with dementia are a highly vulnerable group within this setting (Sampson et al 2009, Featherstone, Northcott & Bridges, 2019). For a person living with dementia an acute hospital admission is closely

associated with significant functional decline (Mukadam and Sampson, 2011), with a markedly higher risk of short-term mortality (Sampson, et al, 2013).

NHS organizations and nursing, increasingly recognise this, and in response emphasise the importance of nursing practice that is 'person centred', or the requirement for caregivers to recognise the individual at the heart of care, rather than caring for a condition (Clissett et al 2013, Ballard et al 2018, Prato et al 2018). While debates continue about what this means for practice, there is evidence that ward staff often miss opportunities to promote the personhood of people living with dementia (Clissett et al 2016, Houghton et al 2016). At the acute hospital level, the organisational response has been the introduction of a number of technologies with the goal of facilitating attention and supporting ward staff to recognise a person living with dementia and respond to the needs of this population.

It has been argued that caution must be exercised towards the enthusiasm for technological 'fixes' for dementia (Gordijn, ten Have, 2016). Although the technologies of attention that we consider here, in terms of signage displayed on wards designed to draw attention to a diagnosis or to a specific deficit such as cognitive impairment, is materially simple and relatively unsophisticated, we nonetheless consider it a form of technology that can also suffer from some of the shortcomings that other technological approaches to dementia may exhibit (Jongsma and Sands, 2018). Impotantly, the ways in which we conceptualise dementia will help determine how we 'see' the condition, and in turn, how we 'see' and approach individual patients (Innes and Manthorpe 2013). Technological solutions tend to focus upon the biological facets of dementia,

whereas to understand the experience of particular, individual patients, requires much more than a mediated and reductionist approach encouraged by an overemphasis on technology (Jongsma and Sands, 2018).

Here we examine the ways in which hospitals and the wards within them employ a range of specific signs and symbols, and we explore their unintended consequences for older people, people living with dementia, and ward staff. We consider the different 'technologies of attention' used, the rationales for their introduction and use, their impact, and whether they might inadvertently be producing further invisibilities.

Methods

Ethnography involves the in-depth study of a small number of cases, studying people's actions and accounts within their natural everyday settings, collecting relatively unstructured data from a range of sources (Hammersley and Atkinson, 1989).

Importantly, it can take into account the perspectives of patients, carers, and hospital staff (Caracelli, 2006). Our approach to ethnography is informed by the symbolic interactionist research tradition (Housley and Atkinson, 2003), which aims to provide an interpretive understanding of the social world, with an emphasis on interaction, focusing on understanding how action and meaning are constructed within a setting (Housley and Atkinson, 2003). The value of this approach is the depth of understanding and theory generation it can provide (Hammersley, 1987).

The goal of ethnography is not representation, but to identify social processes within the data. There are multiple complex and nuanced interactions within these clinical settings that are capable of 'communicating many messages at once, even of subverting on one level what it appears to be "saying" on another' (Turner and Bruner 1986:24). Thus, it is important to observe interaction and performance; how everyday care work is organised and delivered. By obtaining observational data from within each institution on the everyday work of hospital wards, their family carers and the nursing and health care assistants who carry out this work, we can explore the ways in which hospital organisation, procedures and everyday care impact on care during a hospital admission. It remedies a common weakness in many qualitative studies, what people say in interviews may differ from what they do or their private justifications to others (Charmaz and Mitchell, 2001).

We employed the analytic tradition of grounded theory whereby data collection and analysis are interrelated (Glaser and Strauss, 1967; Corbin and Strauss, 1990) and carried out concurrently (Green, 1998; Suddaby, 2006). The flexible nature of this approach is important, because it allowed us to increase the 'analytic incisiveness' (Charmaz and Mitchell, 2001:160) of the ethnography: as data is collected in one site, preliminary analysis of this will proceed in parallel, with this preliminary analysis informing the focus of later data collection within the next site and the further stages of analysis.

Thus, sampling requires a flexible, pragmatic approach and purposive and maximum variation sampling was used. This included 5 hospitals selected to represent a range of hospitals types, geographies and socio-economic catchments. These sites represented a range of expertise and interventions in caring for people with dementia, from no formal expertise to the deployment of specialist dementia workers. Fractures, nutritional disorders, urinary tract infection and pneumonia (Sampson et al 2009, Pinkert & Holle 2012) are among the principal causes of admission to acute hospital settings amongst people with dementia. Thus, we focussed observation within Trauma & Orthopaedic wards (80 days) and Medical Assessment Units (75 days).

Across these sites, 155 days of observational fieldwork were carried out. At each of the 5 sites a minimum of 30 days observation took place, split between the two ward types. Observations were carried out by two researchers, each working in clusters of 2 to 4 days over a 6 week period at each site. A single day of observation could last a minimum of two hours and a maximum of 12 hours. A total of 684 hours of observation were conducted for this study. This produced approximately 600,000 words of observational fieldnotes that were transcribed, cleaned and anonymised (by YY and ZZ). We also carried out ethnographic (during observation) interviews with Trauma and Orthopaedic ward (192 ethnographic interviews and 22 group interviews) and Medical Assessment Unit (222 ethnographic interviews) staff (including nurses, Health Care Assistants (HCAs), auxiliary and support staff and medical teams) as they cared for this patient group. This allowed us to question what they are doing and why, and

what are the caring practices of ward staff when interacting with people living with dementia.

The findings of this research have been discussed in a series of public consultation events and co-creation workshops with nurses (September 2017) and with people living with dementia and their families and carers (February 2018, February 2019) to test and refine our analysis through respondent validation (Birt et al, 2016). Ethics Committee approval was granted by the NHS Research Ethics Service via the Wales Research Ethics Committee (15/WA/0191) and accepted by Health and Care Research Wales. The committee approved this research project for the purposes of the Mental Capacity Act 2005 and confirmed that complies with section 31 of the Act in relation to research carried out as part of this project on, or in relation to, a person who lacks capacity to consent to taking part in the project.

Results and analysis: Signs and symbols as technologies of attention

Within the acute setting, signs and symbols are enrolled to drive attention to the existence, diagnosis, and needs of people living with dementia. The tasks of seeing 'dementia', the person living with dementia, and the essential bedside care needs of this patient population, have given rise to the introduction of an array of technical products within the acute setting. However, these technologies of attention also bring about specific types of visibilities and invisibilities of the person living with dementia and in turn, shape understandings of both the condition and older people within the ward.

Here we explore the varied ways in which technologies designed to bring attention to people living with dementia within the ward may paradoxically have the reverse effect, instead reinforcing the invisibility of people living with dementia and older people generally. This paper will examine the ways in which well-intentioned common practice such as the use of symbols, material objects, and documentation may inadvertently contribute to a culture that does not respond to the needs of people with dementia or the wider population of older people within acute wards.

Visual technologies of attention found within acute wards:

Signage of diagnosis

Numerous small technologies of attention, in the form of visible and potentially temporary embellishments are now commonly used within wards to signify conditions such as 'dementia', with the goal of alerting busy staff to the specific needs of this patient group. These typically consists of signage placed at the bedside or on semi-public patient boards. Patient boards range from whiteboards at the entrance of bays or behind the nurses station, to digital displays on monitors around the ward. Signage varies, but typically takes the form of a small number of symbols, typically in the colour blue, including a blue butterfly, blue flower (forget-me-not), or dragonfly, to signify that the patient at that bedside has a diagnosis of dementia. Such schemes are designed to be implemented as a 'whole hospital scheme', and explicitly aim to inform the large number of staff that will interact with each patient, of their diagnosis and needs. There is some variation in the technology (electronic boards, white boards, laminated stickers or magnetic strips), signage (orange variants of symbols for suspected diagnosis, for

example) and size (although there was some variation, these graphics were typically the paper size A7 or smaller) used from hospital to hospital and ward to ward. Importantly, their usage is as widely accepted as representing 'dementia friendly' good practice within this setting.

Documentation of the person

In response to the perceived challenge of recognising the person with dementia as an individual person, the bedside form 'This is Me', now in its fourth edition, has been introduced with a goal to help staff to see the person, the individual with dementia they are caring for. 'This is Me' can be found across care settings and was used in all of the wards. 'This is Me' was developed by the Alzheimers Society in the UK, a variant of the internationally used one page personal profile (Bailey & Clover 2015) and is simply a short, written record of a patients cultural and family background, history, interests and preferences.

All ten ward sites within the study used the 'This is Me' forms, which would be either located in a folder at the foot of a patient's bed or, more often, kept within the patient medical records, in a record trolley or at the foot of the patient's bed. Senior and specialist ward staff would often proudly display these forms to the research team during prelimary visits to the wards, and there use was always advertised on ward notice boards. However, over 680 hours of observation we only once saw this form

being used in consultation with a patient, when a student nurse briefly scanned it as she supported a person eating their lunch.

We found that family carers and people living with dementia were typically very supportive of the use of visual prompts and documentation, seeing them as a way to alert staff to an individual's specific needs. However, it was a common frustration that these were rarely used or referred to by hospital staff:

Two people living with dementia discuss the initiative 'All About Me'... They both felt that too often, these very unique documents would then languish unseen in filing cabinets: 'It has a lot of value but always put in drawer, not rocket science to use it but never is'. [Public consultation event, February 2018]

In practice, these detailed technologies, such as 'This is Me', become subsumed within the patient medical records, wider paperwork, and busyness of each ward. These documentary technologies are also made obsolete in practice by the more immediately visible signage representing dementia, reinforcing the invisibility of the person on the ward at the expense of the visibility of their diagnosis.

Visibility of the ward as 'dementia friendly'

A number of acute wards within the study identified as being 'dementia friendly'.

Importantly, wards did not signal this via adjustments to the organisation of care within

the ward or supporting increased expertise of ward staff, but instead, this typically

focussed on designating specific space within the ward by adding to the signage and equipment within it.

This indicates the central role that such signage is given within organisational strategies to accommodate people living with dementia. This ward, for example, had signage at the entrance to a six-bedded, high dependency bay indicating a range of practices and strategies in place that made it 'dementia friendly'. These include clinical aspects (pain assessment), practical strategies that increase the visibility of clocks and crockery (although the coloured crockery was not seen in use, they had clocks and used red trays at mealtimes), while some had a less immediately identifiable presence on the ward, such as 'memories' and 'education':

A and B bays are the dementia high dependency bays, opposite the nurses' station. A glass wall has laminated signs on it that state it 'is a dementia friendly ward and environment' in a blue laminated cloud. 'pain assessment, This is Me', 'memories', 'clocks', 'education' and 'coloured crockery'. 'We are introducing coloured crockery in red to help people with dementia and problems with appetite' 'Coloured crockery helps the food on the plate stand out and has been shown to improve the dietary intake of patients'. 'We also encourage families to bring in coloured cups and feeding aids for their relatives'. [Site A]

However, little else that could signify an adapted environment was visible or was routinely used. As in this case, adaptation was often limited to a 'Dementia Friendly' notice board, illustrated with blue forget-me-not flowers and butterflies, which were

prominently displayed within wards. Such boards typically promoted the wards use of 'This is Me' style documents.

The designation of a ward as 'dementia friendly' was often little more than an administrative exercise that was important for the external profile of the ward, for Care Quality Commission inspectionsⁱ and for visitors, rather than representative of a systematic recognition and expertise in the care of people living with dementia. Their usage and meaning appeared to have transformed over time to reflect wider local practices, with the technologies promoted (This is Me forms) or adaptions installed (televisions fitted with vintage fascia, 'memory boxes' of personal belongings and mementos) rarely if ever used.

The promotion of dementia friendly initiatives within each ward suggest an understanding of the importance of person centred approaches towards caring for people living with dementia on each ward. However, the promotion of such initiatives often worked in opposition to these approaches, highlighting the visibility and presence of dementia on the ward, but doing little to support the person.

Signage to direct care may draw attention incorrectly

We found that the technologies of attention used in the wards may not function as intended. We have seen how the 'This is Me' forms may be mandated but routinely ignored. These signs and symbols could also easily become misaligned, with a range of

consequences for the care people living with dementia and older people received. An example of this is taken from a single 6 bed bay, where magnetic signs (the size of fridge magnets) were attached to whiteboards above patient beds to signify diagnosis and care needs. Examination of each patients formal diagnosis, viewed by consulting each patients notes, rarely matched the signage at the bedside.

no blue flower.

307 B1 - Diagnosis in notes: Formal diagnosis of dementia – Signage - No sign
308 B2 – Diagnosis in notes: No dementia, self care – Signage: Mealtime support
309 B3 – Diagnosis in notes: Formal diagnosis of dementia – Signage - No sign
310 B4 – Diagnosis in notes: Formal diagnosis of dementia – Signage: Blue flower
311 B5 – Diagnosis in notes Formal diagnosis of dementia – Signage: Mealtime
312 support, no blue flower.
313 B6 – Diagnosis in notes: Formal diagnosis of dementia – Signage: Nil By Mouth,

In this instance of 5 patients with a formal diagnosis of dementia only 1 had the accepted ward signage (the blue flower) to highlight this, while other patients were either unsigned, mis-signed, or only drew attention to a single aspect of their condition. The example provided was an everyday occurrence within all these wards, and also occured on wards that utilise digital signage. Despite its promotion institutionally, it was also not uncommon for there to be no signage at the bedside to indicate a diagnosis of dementia, regardless of the prevalence of dementia within individual wards:

'There are currently no blue flowers or folders on any of the bays. Doctors and nurses at the station tell me that they are aware of the blue flower scheme but it

has not been implemented. RN from B bay decides B1 should have a blue flower. He is an elderly gentleman only just admitted to the ward, sat up on his bed, alert, and happily chatting to the patient in the bed opposite, who reassures him he shouldn't be here long. As they chat the nurse takes a blue flower and sticks it next to his name on the board above the bed. The doctor is worried that the flowers will be left up for non-dementia patients admitted later, recounting how often the patient name is not changed after a transfer. [Site A day 1]

We identified that signage and people often moved independently of each other and it was not unusual within these wards for a person living with dementia to be moved to another location or discharged, yet the laminated sign and label representing 'dementia', to remain, becoming detached from them, and instead attached to the next person. This not only risks misunderstandings within the ward, with patients inadvertently receiving inappropriate care or erroneous understandings of the needs of that person, but also risks the erosion of the visibility of the sign itself. If staff know the signs are often inaccurate they cease to provide visibility, and instead contribute to the invisibility of dementia within the ward.

Signage results in particular types of care work produced for people living with dementia. We found that the use of signage indicating dementia led to broad and potentially false assumptions about care needs; this conflicted with the purpose of signs, to provide focused care appropriate for the individual. People living with dementia were often

very capable of many types of self-care during their admission (eating meals, walking independently, being continent); however, this was typically independence that was denied by the associated signage, which impacted on ward understandings of dementia. Signage reinforced the organisational expectations that typically people living with dementia needed high levels of support at mealtimes, would not be able to walk independently or were considered at high risk of falls, with incontinence often presumed. This informed routine care practices that limited opportunities for people living with dementia to rehabilitate and regain their independence.

Signs with different symbolic meanings may in practice be conflated:

Signage indicating dementia could lead to generalised understandings of patient needs.

The use of signposts such as the red trays, alongside the ward staff's collective understandings of dementia, meant that it was an everyday and common assumption that most people living with dementia were not able to eat without assistance. Thus, the

different meanings of signage were often conflated.

One example of this is the established practice of using red trays to highlight patients who may need assistance at mealtimes, a system prone to mistakes as there are frequently not enough red trays on a ward or unit, leaving some patients needs invisible to staff. The use of these red trays additionally marked out people living with dementia to be a 'feeder', a common descriptor used by ward staff to denote someone that requires 'feeding'. This could be applied to people, even if they demonstrated during other shifts that they could eat independently or with minimal support. The language of 'feeding' and of 'feeder' is in itself troubling. In the English language, such

vocabulary is generally applied to animals or small children, and hence acts as a dehumanising label for adults. This dehumanisation is compounded by the often inappropriate and inaccurate way in which this patient category could be identified. Often when examining the medical records (case studies) or talking to carers and families, these individuals had been living at home and eating meals independently, however, within the ward this independence became eroded and overshadowed by local ward-based understandings of their condition. Instead they were often spoon-fed meals by HCAs, auxiliary staff or volunteers. This has longer term consequences, for example it could lead to a person losing or not being able to regain skills and independence and have implications for how staff saw them and their abilities.

We observed many people living with dementia who, on the occasions it was permitted, typically due to staff being unavailable, were able to eat independently, but were still classified as requiring support because of their diagnosis. In one example, a person with dementia wanted to read the newspaper before eating, was able to provide droll quips to the ward team in conversation as he was served, and displayed awareness of his surroundings. However, his diagnosis of dementia overrode this. This meant he was viewed by staff as a patient who required 'feeding', rather than a person who could be left to eat a meal. This often overlooked how unnatural spoon feeding can be, especially for a person typically able and used to eating independently. In the example below, ward staff make several decisions about his breakfast without consulting him. Later, when he is left alone with his breakfast he is able to eat it by himself:

This 86-year-old man with a diagnosis of dementia looks tiny, his body swamped by the sheet and blanket covering him, and propped up at an awkward angle to the side of the bed. HCA to the nurse: 'We have three feeds can you help?' The HCA goes over, waking him by announcing 'Breakfast time! Breakfast time! Shall I sit you up?' She takes a large bowl of cornflakes and cutlery over on a red tray and places it on his table. She leans over the side rails of his bed, close to his face, and talks gently to him. While she is doing this the nurse says, 'He won't eat all that', signalling a full bowl of cornflakes, and tips half out into the bin before putting the bowl back. The HCA then says, 'Here you go, here is some breakfast for you'. She tilts the back of the bed up slightly so that he is raised up, but his body doesn't move and he looks in a very uncomfortable position lying to one side of the bed. The HCA repeats his name gently, moving the trolley near him, putting a spoon and bowl near him and presenting him with a spoon of cornflakes, he takes a mouthful and munches it. 'Yes, it is cornflakes, like vesterday' she says. Her face is very close to his face and she strokes hair from his face, 'You are in a good mood today!'... he is still at an odd angle. The HCA is called away and so the trolley with the rest of the cornflakes in a bowl is in front of him. It is fixed at quite a high level and is at almost his shoulder height. He is very tiny and frail and he lifts the metal spoon in his hand and very slowly and shakily he puts the spoon in the bowl and brings a spoon of cornflakes to his mouth. He continues very slowly, shakily and methodically. He eventually puts the spoon down on the tray and picks up the paper bowl and puts it to his mouth

390

391

392

393

394

395

396

397

398

399

400

401

402

403

404

405

406

407

408

409

410

411

to drink from it. He is very shaky and slow and continues to put it down on the tray and then to his mouth until he drains it completely. This seems to take a huge amount of energy and he slowly takes the sheet and wipes his mouth and lies back and closes his eyes. [site B day 4]

Importantly, as above, these judgements typically assumed dependence, and rarely included discussing the person's individual needs. Instead, other members of staff were routinely consulted to give their evaluation of the person, typically when the busy work of mealtimes was already underway. Hence, the visual signage acted in some cases to hamper verbal communication, and lead to an assumed lack of physical ability or mental capacity, in contradistinction to the purpose of improving staff understanding of

Older people and people living with dementia remain invisible or misidentified

individual patient needs and capacities.

These ad-hoc categorisations and subsequent signage of older people, made on the fly by staff in the process of delivering care, do not leave room for the person themselves.

Despite signage, notions of who had or does not have dementia on wards is likely to be driven by perceptions of what behaviours are indicative of dementia.

Despite the high numbers of people living with dementia observed in acute wards, staff within them still did not perceive this to be a significant population within these wards, nor their core patient group. Instead the 'dementia patient' became a very specific type and classification of the older patient, one with significant dependency and behavioural features of the condition and almost always viewed as being at the 'later stages' of the

condition. In contrast, many people living with dementia who were not viewed as behaviourally 'disruptive' were less visible to ward staff, even when they had a diagnosis or a symbol attached to them at the bedside. This typically resulted in older people and people living with dementia who were viewed as 'disruptive' receiving additional focus and those who were quiet, withdrawn or described as 'sleepy' becoming invisible to staff.

Here, the senior nurse in charge of the ward described the various signage and pieces of equipment in place to identify and support people living with dementia. She pointed out the small 'dragonfly' symbol they used on the admission boards, visible to anyone visiting the ward. She explained that they did not have many people living with dementia currently admitted to the ward. Instead, she singled out one man who was a long-term admission, whom she described as 'disruptive', had behavioural issues, high care needs and had been 'specialed'ii. Later when viewing the admission board, there were many more dragonfly symbols there, suggesting that this senior nurse equated a diagnosis of dementia within a narrow definition of 'disruptive', and as she acknowledged, the older people who she described as 'withdrawn' or 'have no self-awareness' become invisible:

We are in the sister's office in the ward and she explains to me that the 'dragonfly' is the symbol they use, but only on the white boards (not above the bed) for known dementia diagnosis: 'We have lots of patients with delirium, infections, mental health, not coping at home, we had one person with lice!' [...] 'We have one (a person with dementia) who is in a side room and has had falls

and bronchitis. He is specialed. He was in a different ward three months before.

The care homes come and see him but when they hear his history they won't take him. Some (one-to-one agency staff) are engaged and others just sit and look at them. They are not under my remit so I can only encourage them...but we do get some fantastic people who engage them with music and the telly.'

I press her: is there only one patient with dementia on the ward?

'No one else with disruptive dementia, more who have a lower level of awareness, neglect and self-awareness. Those that get the attention are the really disruptive ones. The ones who are withdrawn and have no self-awareness are those they get less attention [Site D day 1 F2]

Thus, the symbols themselves are subject to interpretation and over time can transform into a working definition of dementia that the ward finds most useful, that focusses

working of the ward.

Importantly, unlike most other conditions, dementia, and the signage that accompanies it within the acute setting, is a diagnostic label within the ward that once attached to an older person may not be questioned and can quickly be assumed to be a certainty. This can then enter staff understandings of individual patients and the ward population during that shift. It was common for different staff within a ward to have different views of an older patient's diagnosis, which then impacted on how they were cared for, their placement in the ward, and their care and discharge pathways. The example below comes from speaking to a range of staff working within a single bay

attention on older patients who are viewed as 'disruptive' to the timetables and

over the course of an hour. The older patients within one large 9-bed bay were initially classified by ward staff as predominantly living with dementia; however, the older person's nurse was not sure who had a diagnosis of dementia within the bay and the dementia-specialist worker refuted this classification locating the patients with dementia in a different room within the unit:

478

479

480

481

482

483

484

485

486

487

488

489

490

491

492

493

494

495

496

497

498

The Ward Sisters guide me to a closed off bay of 9 beds. They tell me this is where the most patients with dementia have been admitted that morning (consistent with discussion in nurses' handover meeting), and where I am best to make observations [...] I speak to the specialist old person's nurse. She is only assigned to certain patients based on their age/admission/diagnosis and does not have access to the notes of patients to whom she is not assigned. None of the patients she is assigned to today have a formal diagnosis of dementia, she says this is unusual. Her tone of voice when discussing diagnosed dementia implies there may be undiagnosed cases...... I speak to (another dementia worker) who confirms that there are no diagnosed dementia patients on the ward under observation and only 5 on the whole of AMU today and all on the ladies' bays. She says that it can all change very quickly. She tells me the volume is always random, you cannot predict it and it can change very quickly.....Discuss lack of patients with a dementia diagnosis with the RN in charge. Point out that in the handover meeting at the start of the shift it was acknowledged by the Matron that there was both dementia and resistance and refusal on this bay, and that she

seemed to believe that people living with dementia were everywhere today. (Site B Day 1)

Misclassification and re-classification of which older person does and does not have dementia within a ward was typically made quickly during a shift, often in response to how a person looked or was acting, rather than in consultation with their medical records. An assessment of 'confusion', 'refusal' or 'aggression' were often interpreted by ward teams as a sign of dementia.

Discussion

A common institutional approach to a recognised or seemingly intractable problem is to seek technological innovation. However, as we show, there is something fundamentally resistant about the social world of the ward in the face of such technological fixes. We found the use of such technologies to be nested within a context of wider cultural understandings.

The signs and symbols, the 'technologies of attention' we have examined were all introduced with the laudable intentions of assisting the identification of care needs of hospitalised older people, and of acting as reminders that such people are individual persons. However, somewhat ironically, these technologies themselves quickly become invisible and blended into a wider ocean of signage, posters and notices, medical records and forms that proliferate in the ward.

These technologies of attention can only perform their function if the understanding underpinning and generated by the signage is accurate to the condition

and to the individual. However, the signage we observed often reinforced generalised assumptions about older people and understandings of dementia, which further effaced the complexity of the condition. Global ideas about dementia became interpreted within the wards in ways likely to increase deconditioning, and to reduce the person's opportunities for rehabilitation, in conflict with the purpose of the signage. Regardless of the ways in which dementia impacted on the individual, ward staff typically identified and supported people with an assumption of high dependency as a long-term feature of their situation, rather than potentially reflecting the impacts of their acute admitting condition. This could lead in turn to the unintended consequence of inappropriate care.

Moreover, these technologies were often working in direct conflict with each other. The signage used to indicate a dementia diagnosis appeared to lead to outcomes directly at odds with the aim of the intended person-centred technologies. Instead, the over-generalised interpretation of signs, their slippage in meaning, slippage from patient to patient, erroneous labelling of patients with inaccurate diagnoses, and the way in which interpretation of signs may actually reduce opportunities for dialogue with patients, in effect may act to dehumanise older patients and may lead to false or overstated assumptions of lack of capacity. There is an irony in that technologies of attention which are designed to overcome narrow task-based attention, to remind carers of the person centred needs of patients, may not only fail to do this, they may make the situation worse by narrowing attention on the (often misread or incorrect) messages of the signage, which in turn, can lead to invisibility of the person and increased stigma.

The development and promotion of the 'This is Me'-style technology also assumes staff need to know this individual person and their biography to deliver person-centred care. The form includes sections about a person's life, consistent with certain philosophical assumptions about personhood. But in the fast-paced timetabled work and pressurised culture of the acute ward, where these forms were ignored, the focus could more helpfully be on seeing accurately the older person's present and pressing needs. Technologies of attention resting upon certain specific constructions of the person may be less pertinent than care focused upon the specific and immediate needs of each individual.

By focussing on signalling the older person as having dementia, the signage used within these wards may actually reduce staff's ability and opportunities to see the person. In the absence of nuance to signal how dementia impacts on each individual person, signage may become markers of stigma, with a label of dementia which overshadows the person, masking their individual needs, and becomes their master identity (Goffman 2009). 'Personhood' philosophically may be theorised as the possession of certain capacities; the signage however may lead to assumptions of lack of capacity, for example as was seen in the assumption that a dementia diagnosis equated with the need for assistance with mealtimes and visual signage acts to override verbal communication; the isolation of the person living with dementia is increased and opportunities for interactions, which may be vital to identify and assess signs and symptoms associated with their admitting condition or the negative impacts of hospital

admission may be missed (c.f. George et al, 2013), while those helpful to signal the need for appropriate timely bedside care and rehabilitation may be missed.

564

565

566

567

568

569

570

571

572

573

574

575

576

577

578

579

580

581

582

583

584

585

The use of signage fits with encouraging a form of attention focused on specific features of an individual person. In the absence of accurate, individually tailored understandings of what a label of 'dementia', or the need for assistance with eating, means for each person, such technologies of attention will not fulfil their purpose. Receptive attention, focused on each individual person more globally, may be more appropriate. However, in the context of the organisation and delivery of task-based care, with a focus on speed at the bedside, make this latter form of attention hard to achieve (Featherstone, Northcott & Bridges 2019, Featherstone et al 2019). The signage frequently acted to simplify and stereotype staff interactions with patients. A drive for goal directed efficiency may also lie behind the implementation of the signage that could make it even harder to achieve. At the very least, improved understandings of the variable aetiology and impacts of dementia, and the highly variable and often fluctuating needs of each individual person, particularly the impacts of an acute admission and the acute hospital setting itself, are needed.

Research has typically focused on examining the introduction and impacts of technoscience into the clinical sphere. However, by looking at these small seemingly mundane technologies of attention that by their size and materiality seem benign, we show that they can have powerful impacts. Their low cost, apparent simplicity of introduction, and their promotion by third sector and nursing organisations mean that they are generally seen as a good thing. But as we have shown, they have real and

powerful consequences for the work of the ward, and the way hospital staff see and make sense of dementia.

These technologies of attention will continue to proliferate and there are many more that we have not explored that are currently being introduced into our hospitals. However, and as with so much of the routine bedside work of the acute ward, none are evidence-based (Shekelle et al 2013). Their introduction and use also allows hospital trusts to signal that they are responding and supporting persons with dementia, but importantly, it also means they can use these technologies to circumvent calls for strategic and significant investment to support ward staff and patients, and in turn reduces institutional motivation for the provision of expertise in the care of people living with dementia for all staff within acute hospital wards.

References

Alzheimer's Society, 2016.

Atkinson, P. and Atkinson, P.A., 1995. Medical talk and medical work. Sage.

Bailey G. and Clover T. 2015. 'Using one-page profiles to create care plans' Australian

Journal of Demenita Care August 2015

Ballard, C., Corbett, A., Orrell, M., Williams, G., Moniz-cook, E., Romeo, R., Woods, B.,

Garrod, L., Testad, I., Woodward-, B., Wenborn, J., Knapp, M., Fossey, J., 2018.

Impact of person-centred care training and person-centred activities on quality of

life, agitation, and antipsychotic use in people with dementia living in nursing

homes: A cluster-randomised controlled trial. PLoS medicine, 15(2), e1002500

609	Berg, M., 1992. The construction of medical disposals: Medical sociology and medical
610	problem solving in clinical practice. Sociology of Health & Illness, 14(2), pp.151-180.
611	Birt, L., Scott, S., Cavers, D., Campbell, C., & Walter, F. 2016. Member Checking: A Tool
612	to Enhance Trustworthiness or Merely a Nod to Validation? Qualitative Health
613	Research, 26(13), 1802–1811.
614	Caracelli, V. J. 2006. Enhancing the policy process through the use of ethnography and
615	other study frameworks: A mixed-method strategy. Research in the Schools, 13(1),
616	84-92.
617	Charmaz K., Mitchell RG. "Grounded theory in ethnography" in Atkinson P. (Ed)
618	Handbook of Ethnography, 2001, 160-174. Sage: London
619	Clissett, P., Porock, D., Harwood, R. H., & Gladman, J. R. F. (2013). The challenges of
620	achieving person-centred care in acute hospitals: A qualitative study of people
621	with dementia and their families. International Journal of Nursing Studies,
622	50(11), 1495–1503.
623	Corbin, J.M., Strauss, A., "Grounded theory research: Procedures, canons, and
624	evaluative criteria." Qual. Sociol. 1990, 13, 3–21.
625	Cowdell, F., 2010. The care of older people with dementia in acute
626	hospitals. International journal of older people nursing, 5(2), pp.83-92
627	Featherstone, K., Northcott, A. & Bridges, J. 2019. 'Routines of resistance: An
628	ethnography of the care of people living with dementia in acute hospital wards
629	and its consequences', International Journal of Nursing Studies 96, pp 53-60

630	Featherstone K, Northcott A, Harden J, Harrison-Denning K, Tope R, Bale S & Bridges J
631	2019 'Refusal and resistance to care by people living with dementia being cared
632	for within acute hospital wards: an ethnographic study.' Health Service Delivery
633	Research 2019:7(11)
634	Glaser, B. and Strauss, A., 1967. The discovery of grounded theory. London: Weidenfeld
635	and Nicholson, 24(25), pp.288-304.
636	Goffman, E., 2009. Stigma: Notes on the management of spoiled identity. Simon and
637	Schuster.
638	Gordijn, B., ten Have, H. 2016. Technology and dementia. Medicine, Health Care and
639	Philosophy 19(3) 339-340.
640	Hammersley, M., (1987) What's Wrong with Ethnography? Methodological Explorations.
641	London: Routledge
642	Hammersley, M., Atkinson, P., 1989. Ethnography: Principles in practice. London: Routledge.
643	Heidegger, M., 1996. Being and time: A translation of Sein und Zeit. SUNY Press, Albany
644	NY
645	Housley, W., & Atkinson, P. (2003). Interactionism, Sage. London
646	Houghton, C., Murphy, K., Brooker, D., Casey, D., 2016. Healthcare staffs' experiences
647	and perceptions of caring for people with dementia in the acute setting:
648	Qualitative evidence synthesis. Int. J. Nurs. Stud. 61, 104–11
649	Innes, A., Manthorpe, J. 2013. Developing theoretical understandings of dementia and
650	their application to dementia care policy in the UK. Dementia 12(6): 682-696.
651	Jongsma, KR., Sand, M. 2017 The usual suspects: why techno-fixing dementia is flawed.

652	Medicine, Health Care and Philosophy 20(1) 119-130.
653	Levy B (2009) Stereotype embodiment: A psychosocial approach to aging. Current
654	directions in psychological science 18 (6):332-336
655	McGilchrist, I., 2009. The master and his emissary. The Divided Brain and the Making of the
656	Western world. Yale.
657	MacNaughton, D., 1988. Moral vision: an introduction to ethics. Blackwell. Oxford
658	Mol, A., 2002. The body multiple: Ontology in medical practice. Duke University Press.,
659	Durham NC
660	Mukadam, N. and Sampson, E.L., 2011. A systematic review of the prevalence,
661	associations and outcomes of dementia in older general hospital
662	inpatients. International Psychogeriatrics, 23(3), pp.344-355.
663	Norman, R., 2006. Observations of the experiences of people with dementia on general
664	hospital wards. Journal of Research in Nursing, 11(5), pp.453-465.
665	Pinkert, C., Holle, B., 2012. People with dementia in acute hospitals. Literature review of
666	prevalence and reasons for hospital admission. Z. Gerontol. Geriatr. 45, 728-734.
667	https://doi.org/10.1007/s00391-012-0319-1
668	Prato, L., Lindley, L., Boyles, M., Robinson, L., Abley, C., 2018. Empowerment,
669	environment and person-centred care: A qualitative study exploring the hospital
670	experience for adults with cognitive impairment. Dementia.
671	https://doi.org/10.1177/1471301218755878

672 Sampson, E., Blanchard, M., Jones, L., Tookman, A., & King, M. (2009). Dementia in the 673 acute hospital: Prospective cohort study of prevalence and mortality. *British* 674 Journal of Psychiatry, 195(1), 61-66. doi:10.1192/bjp.bp.108.055335 675 Sampson, E.L., Leurent, B., Blanchard, M.R., Jones, L. and King, M., 2013. Survival of 676 people with dementia after unplanned acute hospital admission: a prospective 677 cohort study. *International journal of geriatric psychiatry*, 28(10), pp.1015-1022. 678 Shekelle, P.G., Pronovost, P.J., Wachter, R.M., McDonald, K.M., Schoelles, K., Dy, S.M., 679 Shojania, K., Reston, J.T., Adams, A.S., Angood, P.B. and Bates, D.W., 2013. The 680 top patient safety strategies that can be encouraged for adoption now. Annals of 681 Internal Medicine, 158(5_Part_2), pp.365-368. 682 Suddaby, R. (2006). "From the editors: What grounded theory is not." Academy of 683 management journal, 49(4), 633-642. 684 Tadd, W., Hillman, A., Calnan, S., Calnan, M., Bayer, T. and Read, S., 2011. Right place-685 wrong person: dignity in the acute care of older people. Quality in Ageing and 686 *Older Adults,* 12(1), pp.33-43. Tadd, W., Hillman, A., Calnan, M., Calnan, S., Read, S. and Bayer, A., 2012. From right 687 688 place-wrong person, to right place-right person: dignified care for older 689 people. *Journal of health services research & policy*, 17(2_suppl), pp.30-36. 690 Thompson, E., 2001. Empathy and consciousness. *Journal of consciousness studies*, 8(5-6), 691 pp.1-32. 692 Tooley, M., 2010. Personhood (pp. 127-139). Wiley-Blackwell.

Turner, V., Bruner, E., 1986. *The Anthropology of Experience* New York: PAJ Publications

693

694 Weil, S., 1952. *Gravity and grace*. U of Nebraska Press, Lincoln NE

ⁱ The Care Quality Commission is the independent regulator of health and social care in England. https://www.cqc.org.uk

ⁱⁱ This was a policy within almost all hospitals and wards as a way to support both people living with dementia and ward staff. In practice, this meant that once a person living with dementia was identified as resisting care within the ward, they could be classified as 'specialed,' a Deprivation of Liberty Order could be obtained and the ward could legitimately request additional support and assign an agency HCAs to provide one-to-one care to manage that person during their admission.

iii A syndrome that comprises a large range of progressive conditions grouped together by a common aetiology of cerebral disease, brain injury or insult that leads to progressive cerebral dysfunction http://apps.who.int/classifications/apps/icd/icd10online2007/index.htm?gf00.htm+