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help or hindrance to care?

Featherstone, Katie, Boddington, Paula and Northcott, Andy (2020) Using signs and symbols to label hospital patients with a dementia diagnosis: help or hindrance to care? *Narrative Inquiry in Bioethics*, 10 (1). pp. 49-61. ISSN 2157-1732

<http://dx.doi.org/10.1353/nib.2020.0026>

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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 efficiency 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

20 achieve the ethical imperative of ensuring that patients are recognised and their needs
21 visible.

22 Objectives and background

23 The importance of attention and of 'seeing' the patient

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

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

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

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

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

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

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

76

77 Hospitals, nursing and seeing the person

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

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

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

97 It has been argued that caution must be exercised towards the enthusiasm for
98 technological 'fixes' for dementia (Gordijn, ten Have, 2016). Although the technologies
99 of attention that we consider here, in terms of signage displayed on wards designed to
100 draw attention to a diagnosis or to a specific deficit such as cognitive impairment, is
101 materially simple and relatively unsophisticated, we nonetheless consider it a form of
102 technology that can also suffer from some of the shortcomings that other technological
103 approaches to dementia may exhibit (Jongsma and Sands, 2018). Importantly, the ways
104 in which we conceptualise dementia will help determine how we 'see' the condition,
105 and in turn, how we 'see' and approach individual patients (Innes and Manthorpe
106 2013). Technological solutions tend to focus upon the biological facets of dementia,

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

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

116

117 [Methods](#)

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

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

128

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

141
142 We employed the analytic tradition of grounded theory whereby data collection and
143 analysis are interrelated (Glaser and Strauss, 1967; Corbin and Strauss, 1990) and
144 carried out concurrently (Green, 1998; Suddaby, 2006). The flexible nature of this
145 approach is important, because it allowed us to increase the ‘analytic incisiveness’
146 (Charmaz and Mitchell, 2001:160) of the ethnography: as data is collected in one site,
147 preliminary analysis of this will proceed in parallel, with this preliminary analysis
148 informing the focus of later data collection within the next site and the further stages of
149 analysis.

150

151 Thus, sampling requires a flexible, pragmatic approach and purposive and maximum
152 variation sampling was used. This included 5 hospitals selected to represent a range of
153 hospitals types, geographies and socio-economic catchments. These sites represented a
154 range of expertise and interventions in caring for people with dementia, from no formal
155 expertise to the deployment of specialist dementia workers. Fractures, nutritional
156 disorders, urinary tract infection and pneumonia (Sampson et al 2009, Pinkert & Holle
157 2012) are among the principal causes of admission to acute hospital settings amongst
158 people with dementia. Thus, we focussed observation within Trauma & Orthopaedic
159 wards (80 days) and Medical Assessment Units (75 days).

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

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

174 The findings of this research have been discussed in a series of public
175 consultation events and co-creation workshops with nurses (September 2017) and with
176 people living with dementia and their families and carers (February 2018, February
177 2019) to test and refine our analysis through respondent validation (Birt et al, 2016).
178 Ethics Committee approval was granted by the NHS Research Ethics Service via the
179 Wales Research Ethics Committee (15/WA/0191) and accepted by Health and Care
180 Research Wales. The committee approved this research project for the purposes of the
181 Mental Capacity Act 2005 and confirmed that complies with section 31 of the Act in
182 relation to research carried out as part of this project on, or in relation to, a person who
183 lacks capacity to consent to taking part in the project.

184

185 [Results and analysis: Signs and symbols as technologies of attention](#)

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

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

200 [Visual technologies of attention found within acute wards:](#)

201 *Signage of diagnosis*

202
203 Numerous small technologies of attention, in the form of visible and potentially
204 temporary embellishments are now commonly used within wards to signify conditions
205 such as 'dementia', with the goal of alerting busy staff to the specific needs of this
206 patient group. These typically consists of signage placed at the bedside or on semi-
207 public patient boards. Patient boards range from whiteboards at the entrance of bays or
208 behind the nurses station, to digital displays on monitors around the ward. Signage
209 varies, but typically takes the form of a small number of symbols, typically in the colour
210 blue, including a blue butterfly, blue flower (forget-me-not), or dragonfly, to signify
211 that the patient at that bedside has a diagnosis of dementia. Such schemes are designed
212 to be implemented as a 'whole hospital scheme', and explicitly aim to inform the large
213 number of staff that will interact with each patient, of their diagnosis and needs. There
214 is some variation in the technology (electronic boards, white boards, laminated stickers
215 or magnetic strips), signage (orange variants of symbols for suspected diagnosis, for

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

220

221 *Documentation of the person*

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

230

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

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

239

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

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

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

253

254 *Visibility of the ward as 'dementia friendly'*

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

256 Importantly, wards did not signal this via adjustments to the organisation of care within
257 the ward or supporting increased expertise of ward staff, but instead, this typically

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

260

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

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

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

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

282

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

291

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

297

298 Signage to direct care may draw attention incorrectly

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

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

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,
314 no blue flower.

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

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

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

331
332 We identified that signage and people often moved independently of each other and it
333 was not unusual within these wards for a person living with dementia to be moved to
334 another location or discharged, yet the laminated sign and label representing
335 'dementia', to remain, becoming detached from them, and instead attached to the next
336 person. This not only risks misunderstandings within the ward, with patients
337 inadvertently receiving inappropriate care or erroneous understandings of the needs of
338 that person, but also risks the erosion of the visibility of the sign itself. If staff know the
339 signs are often inaccurate they cease to provide visibility, and instead contribute to the
340 invisibility of dementia within the ward.

341
342 [Signage results in particular types of care work produced for people living with dementia](#)
343 We found that the use of signage indicating dementia led to broad and potentially false
344 assumptions about care needs; this conflicted with the purpose of signs, to provide
345 focused care appropriate for the individual. People living with dementia were often

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

354 Signs with different symbolic meanings may in practice be conflated:

355 Signage indicating dementia could lead to generalised understandings of patient needs.
356 The use of signposts such as the red trays, alongside the ward staff's collective
357 understandings of dementia, meant that it was an everyday and common assumption
358 that most people living with dementia were not able to eat without assistance. Thus, the
359 different meanings of signage were often conflated.

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

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

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

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

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

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

423

424 [Older people and people living with dementia remain invisible or misidentified](#)

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

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

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

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

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

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

456 and bronchitis. He is specialed. He was in a different ward three months before.
457 The care homes come and see him but when they hear his history they won't take
458 him. Some (one-to-one agency staff) are engaged and others just sit and look at
459 them. They are not under my remit so I can only encourage them...but we do get
460 some fantastic people who engage them with music and the telly.'

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

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

466 Thus, the symbols themselves are subject to interpretation and over time can transform
467 into a working definition of dementia that the ward finds most useful, that focusses
468 attention on older patients who are viewed as 'disruptive' to the timetables and
469 working of the ward.

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

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

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

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

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

506

507 **Discussion**

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

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

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

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

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

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

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

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

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

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

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

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

597

598 References

599 Alzheimer's Society, 2016.

600

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

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

603 *Journal of Dementia Care* August 2015

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

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

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

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

608 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 Jongasma, 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.

687 Tadd, W., Hillman, A., Calnan, M., Calnan, S., Read, S. and Bayer, A., 2012. From right
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.

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

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 'specialied,' 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+>