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The Presentation of the Clothed Self on the Hospital Ward: An ethnographic account of perceptual attention and implications for the personhood of people living with dementia.

Abstract

This study contributes to our understanding of the ‘medical gaze’ and its impact upon the ways in which people living with dementia experience care during a hospital admission. Visual perception has a powerful effect upon our emotional and moral reactions to others. One aspect of how we perceive and respond to others is through clothing, which relates strongly to class and social position. Our focus is on exploring the ways in which patient clothing may affect not only the perceptions and response of others, but also self-perception and resulting behaviour. We draw upon ethnographic research within acute hospital wards in 5 hospitals across England and Wales, examining the everyday organisation and delivery of care to people living with dementia. People living with dementia are a significant population who have poor experiences and outcomes of care within the acute setting. Our data suggests that the twin aspects of clothing and appearance – of self-perception, and of perception by others - may be especially important in the fast paced context of an acute ward environment, where patients living with dementia may be struggling with the impacts of an additional acute medical condition within in a highly timetabled and regimented and unfamiliar environment of the ward, and where staff perceptions of them may feed into clinical assessments of their condition and subsequent treatment and discharge pathways.

Introduction and philosophical background

Work in the medical humanities has noted the importance of the ‘medical gaze’ and how it may ‘see’ the patient in ways which are specific, whilst possessing broad significance, in relation to developing medical knowledge; to diagnosis; and to the social position of the medical profession.¹ Some authors have emphasised that vision is a distinctive modality of perception which merits its own consideration, and which may have a particular role to play in medical education and understanding.^{2,3} The clothing we wear has a strong impact on how we are perceived. For example, commentary in this journal on the ‘white coat’ observes that while it may rob the medical doctor of individuality, it nonetheless grants an elevated status;⁴

1 in contrast the patient hospital gown may rob patients of individuality in a way that
2 stigmatises them⁵, reducing their status in the ward, and ultimately dehumanises them, in
3 conflict with the humanistic approaches seen as central to best practice in the care of older
4 patients, and particularly those living with dementia.⁶

5
6 The broad context of our concern is the visibility of patients and their needs. We draw upon
7 observations made during an ethnographic study of the everyday care of people living with
8 dementia within acute hospital wards, to consider how patients' clothing may impact upon
9 the way they were perceived by themselves and by others. Hence, we draw upon this
10 ethnography to contribute to discussion of the 'medical gaze' in a specific and informative
11 context.

12
13 The acute setting illustrates a situation in which there are great many biomedical, technical,
14 recording, and timetabled routine task-oriented demands, organised and delivered by
15 different staff members, together with demands for care and attention to particular
16 individuals and an awareness of their needs. Within this ward setting, we focus upon patients
17 who are living with dementia, since this group may be particularly vulnerable to a
18 dehumanising gaze.⁶ We frame our discussion within the broader context of the general
19 philosophical question of how we acquire knowledge of different types, and the moral
20 consequences of this, particularly knowledge through visual perception.

21
22 Debates throughout the history of philosophy raise questions about the nature and sources
23 of our knowledge. Contrasts are often drawn between more reliable or less reliable
24 knowledge; and between knowledge that is more technical or 'objective', and knowledge
25 that is more emotionally based or more 'subjective'. A frequent point of discussion is the
26 reliability and characteristics of perception as a source of knowledge. This epistemological
27 discussion is mostly focused on vision, indicating its particular importance as a mode of
28 perception to humans.⁷

29
30 Likewise, in ethics there is discussion of the origin of our moral knowledge and the particular
31 role of perception.⁸ There is frequent recognition that the observer has some significant role
32 in acquiring moral knowledge. Attention to qualities of the moral observer is not in itself a

denial of moral reality; indeed, it is the very essence of an ethical response to the world to recognise the deep reality of others as separate persons. The nature of ethical attention to the world and to those around us is debated and has been articulated in various ways. The quality of ethical attention may vary and achieving a high level of ethical attention may require certain conditions, certain virtues, and the time and mental space to attend to the situation and claims of the other.⁹

Consideration has already been given to how different modes of attention to the world might be of relevance to the practice of medicine. Work which examines different ways of processing information, and of interacting with and being in the world, can be found in Iain McGilchrist's *The Master and His Emissary*,¹⁰ where he draws upon neurological discoveries and applies his ideas to the development of human culture. McGilchrist has recently expanded on the relevance of understanding two different approaches to knowledge for the practice of medicine.¹¹ He argues that task-oriented perception, and a wider, more emotionally attuned awareness of the environment, are necessary partners, but may in some circumstances compete, with the competitive edge often being given to the narrower, task-based attention.

There has been critique of McGilchrist's arguments as well as much support. We find his work a useful framework for understanding important debates in the ethics of medicine and of nursing about relationships of staff to patients. In particular, it helps to illuminate the consequences of patients' dress and personal appearance for how they are seen and treated.

Dementia and personal appearance

Our work focuses on patients living with dementia admitted to acute hospital wards. Here they are a large group, present alongside older patients unaffected by dementia, as well as younger patients. This mixed population provides a useful setting to consider the impact of personal appearance on different patient groups.

The role of appearance in the presentation of the self has been explored extensively by Tseëlon,^{12,13} drawing on Goffman's work on stigma⁵ and the presentation of the self¹⁴ using

1 interactionist approaches. Drawing on the experiences on women in the UK, Tseëlon argues
2 Goffman's interactionist approach best supports how we understand the relationship
3 appearance plays in self presentation, and its relationships with other signs and interactions
4 surrounding it. Tseëlon suggests that understandings in this area, in the role appearance and
5 clothing have in the presentation of the self, have been restricted by the perceived trivialities
6 of the topic and limited to the field of fashion studies¹⁵.

7
8 The personal appearance of older patients, and patients living with dementia in particular,
9 has, more recently, been shown to be worthy of attention and of particular significance.
10 Older people are often assumed to be left out of fashion, yet a concern with appearance
11 remains^{16,17}. Lack of attention to clothing and to personal care may be one sign of the varied
12 symptoms associated with cognitive impairment or dementia, and so conversely, attention to
13 appearance is one way of combatting the stigma associated with dementia. Families and
14 carers may also feel the importance of personal appearance. The significant body of work by
15 Twigg and Buse in this field in particular draws attention to the role clothing has on
16 preserving the identity and dignity of people living with dementia, while also constraining
17 and enabling elements of care within long term community settings.¹⁶⁻¹⁹ Within this paper,
18 we examine the ways in which these phenomena can be even more acutely felt within the
19 impersonal setting of the acute hospital.

20
21 Work has also shown how people living with dementia strongly retain a felt, bodily
22 appreciation for the importance of personal appearance. The comfort and sensuous feel of
23 familiar clothing may remain, even after cognitive capacities such as the ability to recognise
24 oneself in a mirror, or verbal fluency, are lost.¹⁸ More strongly still, Kontos,²⁰⁻²² drawing on
25 the work of Merleau-Ponty and of Bourdieu, has convincingly argued that this attention to
26 clothing and personal appearance is an important aspect of the maintenance of a bodily
27 sense of self, which is also socially mediated, in part via such attention to appearance. Our
28 observations lend support to Kontos' hypothesis.

29
30 Much of this previous work has considered clothing in the everyday life of people living with
31 dementia in the context of community or long-term residential care.¹⁸ Here we look at the
32 visual impact of clothing and appearance in the different setting of the hospital ward and

1 consider the consequent implications for patient care. This setting enables us to consider
2 how the short-term and unfamiliar environments of the acute ward, together with the
3 contrast between personal and institutional attire, impacts upon the perception of the
4 patient by self and by others.

5
6 There is a body of literature that examines the work of restoring the appearance of residents
7 within long term community care settings, for instance Ward et al's work which
8 demonstrates the importance of hair and grooming as a key component of care.^{23,24} The
9 work of Itanen-Tahkavouri²⁵ examines the usage of garments designed for long term care
10 settings, exploring the conflict between clothing used to prevent undressing or facilitate the
11 delivery of care, and the distress such clothing can cause, being powerfully symbolic of lower
12 social status and associated with reduced autonomy^{26,27}.

13
14 Within this literature, there has also been a significant focus on the role of clothing,
15 appearance, and the tasks of personal care surrounding it, on the older female body. A
16 corpus of feminist literature has examined the ageing process and the use of clothing to
17 conceal aging, the presentation of a younger self, or a 'certain' age²⁸ It argues that once the
18 ability to conceal the ageing process through clothing and grooming has been lost, the aged
19 person must instead conceal themselves, dressing to hide themselves and becoming invisible
20 in the process²⁹. This paper will explore how institutional clothing within hospital wards
21 affects both the male and female body, the presentation of the aging body and its role in
22 reinforcing the invisibility of older people, at a time when they are paradoxically most visible,
23 unclothed and undressed, or wearing institutional clothing within the hospital ward.

24
25 Institutional clothing is designed and used, to fulfil a practical function. Its use may therefore
26 perhaps incline us towards a 'task based' mode of attention, which as McGilchrist argues,¹⁰
27 whilst having a vital place in our understanding of the world, may on occasion interfere with
28 the forms of attention that may be needed to deliver good person-oriented care responsive
29 to individual needs.

1 **Methods**

2
3 Ethnography involves the in-depth study of people's actions and accounts within their natural
4 everyday setting, collecting relatively unstructured data from a range of sources.³⁰
5 Importantly, it can take into account the perspectives of patients, carers, and hospital staff.³¹
6 Our approach to ethnography is informed by the symbolic interactionist research tradition,
7 which aims to provide an interpretive understanding of the social world, with an emphasis on
8 interaction, focusing on understanding how action and meaning are constructed within a
9 setting.³² The value of this approach is the depth of understanding and theory generation it
10 can provide.³³

11
12 The goal of ethnography is to identify social processes within the data. There are multiple
13 complex and nuanced interactions within these clinical settings that are capable of
14 'communicating many messages at once, even of subverting on one level what it appears to
15 be "saying" on another'.³⁴ Thus, it is important to observe interaction and performance; how
16 everyday care work is organised and delivered. By obtaining observational data from within
17 each institution on the everyday work of hospital wards, their family carers and the nursing
18 and health care assistants who carry out this work, we can explore the ways in which hospital
19 organisation, procedures and everyday care impact on care during a hospital admission. It
20 remedies a common weakness in many qualitative studies, that what people say in interviews
21 may differ from what they do or their private justifications to others.³⁵

22
23 Data collection (observations and interviews) and analysis were informed by the analytic
24 tradition of grounded theory³⁶. There was no prior hypothesis testing and we utilized the
25 constant comparative method and theoretical sampling whereby data collection (observation
26 and interview data) and analysis are interrelated,^{36,37} and are carried out concurrently.^{38,39}
27 The flexible nature of this approach is important, because it can allow us to increase the
28 'analytic incisiveness'³⁵ of the study. Preliminary analysis of data collected from individual
29 sites informed the focus of later stages of sampling, data collection and analysis in other
30 sites.

Thus, sampling requires a flexible, pragmatic approach and purposive and maximum variation sampling (theoretical sampling) was used. This included 5 hospitals selected to represent a range of hospitals types, geographies, and socio-economic catchments. Five hospitals were purposefully selected to represent a range of hospitals types: two large University teaching hospitals, two medium sized general hospitals and one smaller general hospital. This included one urban, two inner city and two hospitals covering a mix of rural and suburban catchment areas, all situated within England and Wales.

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^{40, 41} 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 (MAU) (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.

Patients within these settings with a diagnosis of dementia were identified through ward nursing handover notes, patient records and board data with the assistance of ward staff. Following the provision of written and verbal information about the study, and the

expression of willingness to take part, written consent was taken from patients, staff and visitors directly observed or spoken to as part of the study.

To optimize the generalizability of our findings⁴² our approach emphasizes the importance of comparisons across sites,⁴³ with theoretical saturation achieved following the search for negative cases, and on exploring a diverse and wide range of data. When no additional empirical data were found, we concluded that the analytic categories were saturated.^{36,44}

Grounded theory and ethnography are complementary traditions, with grounded theory strengthening the ethnographic aims of achieving a theoretical interpretation of the data, whilst the ethnographic approach prevents a rigid application of grounded theory.³⁵ Using an ethnographic approach can mean that everything within a setting is treated as data, which can lead to large volumes of unconnected data and a descriptive analysis.⁴⁵ This approach provides a middle ground in which the ethnographer, often seen as a passive observer of the social world, uses grounded theory to provide a systematic approach to data collection and analysis that can be used to develop theory to address the interpretive realities of participants within this setting.³⁵

Ethical approval for this study was granted by Wales REC3 (15/WA/1901) on 24th June 2015.

Patient and public involvement

The data presented in this paper is drawn from a wider ethnographic study supported by an advisory group of people living with dementia and their family carers. It was this advisory group that informed us of the need of a better understanding of the impacts of the everyday care received by people living with dementia in acute hospital settings. The authors met with this group on a regular basis throughout the study, and received guidance on both the design of the study and the format of written materials used to recruit participants to the study. The external oversight group for this study included, and was chaired, by carers of people living with dementia. Once data analysis was complete, the advisory group commented on our initial findings and recommendations. During and on completion of the analysis, a series of

public consultation events were held with people living with dementia and family carers to ensure their involvement in discussing, informing, and refining our analysis.

Findings

Within this paper we focus on exploring the medical gaze through the embedded institutional cultures of patient clothing, and the implications this have for patients living with dementia within acute hospital wards. These findings emerged from our wider analysis of our ethnographic study examining ward cultures of care and the experiences of people living with dementia. Here we examine the ways in which the cultures of clothing within wards impacts on the visibility of patients within it, what clothing and identity mean within the ward and the ways in which clothing can be a source of distress. We will look at how personal grooming and appearance can affect status within the ward, and finally explore the removal of clothing, and the impacts of its absence.

Ward clothing cultures

Across our sites, there was variation in the cultures of patient clothing and dress. Within many wards it was typical for all older patients to be dressed in hospital-issued institutional gowns and pyjamas (typically in pastel blue, pink, green or peach), paired with hospital supplied socks (usually bright red, although there was some small variation) with non-slip grip soles, while in other wards, it was standard practice for people to be supported to dress in their own clothes. Across all these wards, we observed that younger patients (middle aged/working age) were more likely to be able to wear their own clothes while admitted to a ward, than older patients and those with a dementia diagnosis.

Among key signifiers of social status and individuality are the material things around the person, which in these hospital wards included the accoutrements around the bedside. Significantly, it was observed that people living with dementia were not only more likely to be wearing an institutional hospital gown or institutional pyjamas, but also to have little to individuate the person at the bedside, on either their cabinet or the mobile tray table at their bedside. The wearing of institutional clothing was typically connected to fewer personal items on display or within reach of the patient, with any items tidied away out of sight. In

1 contrast, younger working age patients often had many personal belongings, cards, gadgets,
2 books, media players, with young adults also often having a range of 'Get Well Soon' gifts,
3 balloons and so on from the hospital gift shop) on display. This both afforded some elements
4 of familiarity, but also marked the person out as someone with individuality and a certain
5 social standing and place.

7 **The visibility of patients on a ward**

9 The significance of the obscurity or invisibility of the patient in artworks depicting doctors has
10 been commented on.⁴ Likewise, we observed that some patients within these wards were
11 much more 'visible' to staff than others. It was often apparent how the wearing of personal
12 clothing could make the patient and their needs more readily visible to others as a person.
13 This may be especially so given the contrast in appearance clothing may produce in this
14 particular setting. On occasion, this may be remarked upon by staff, and the resulting
15 attention received favourably by the patient.

17 A member of the bay team returned to a patient and found her freshly dressed in a
18 white tee shirt, navy slacks and black velvet slippers and exclaimed aloud and
19 appreciatively, 'Wow, look at you!' The patient looked pleased as she sat and combed
20 her hair [site 3 day 1].

22 Such a simple act of recognition as someone with a socially approved appearance takes on a
23 special significance in the context of an acute hospital ward, and for patients living with
24 dementia whose personhood may be overlooked in various ways.⁴⁶

26 This question of visibility of patients may also be particularly important when people living
27 with dementia may be less able to make their needs and presence known. In this example, a
28 whole bay of patients was seemingly 'invisible'. Here the ethnographer is observing a four-
29 bed bay occupied by male patients living with dementia.

31 The man in bed 17 is sitting in his bedside chair. He is dressed in green hospital issue
32 pyjamas and yellow grip socks. At 10 a.m., the physiotherapy team come and see him.

1 The physiotherapist crouches down in front of him and asks him how he is. He says he
2 is unhappy, and the physiotherapist explains that she'll be back later to see him again.
3 The nurse checks on him, asks him if he wants a pillow, and puts it behind his head
4 explaining to him, 'You need to sit in the chair for a bit'. She pulls his bedside trolley
5 near to him. With the help of a Healthcare Assistant they make the bed. The
6 Healthcare Assistant chats to him, puts cake out for him, and puts a blanket over his
7 legs. He is shaking slightly and I wonder if he is cold.

8 The nurse explains to me, 'The problem is this is a really unstimulating environment',
9 then says to the patient, 'All done, let's have a bit of a tidy up,' before wheeling the
10 equipment out.

11 The neighbouring patient in bed 18, is now sitting in his bedside chair, wearing (his
12 own) striped pyjamas. His eyes are open, and he is looking around; after a while, he
13 closes his eyes and dozes. The team chat to patient 19 behind the curtains. He says he
14 doesn't want to sit, and they say that is fine unless the doctors tell them otherwise.
15 The nurse puts music on an old radio with a CD player which is at the doorway near
16 the ward entrance. It sounds like music from a musical and the ward it is quite noisy
17 suddenly. She turns down the volume a bit, but it is very jaunty and upbeat. The man
18 in bed 19 quietly sings along to the songs: 'I am going to see my baby when I go home
19 on victory day....'

20 At ten thirty, the nurse goes off on her break. The rest of the team are spread
21 around the other bays and side rooms. There are long distances between bays within
22 this ward. After all the earlier activity it is now very calm and peaceful in the bay.
23 Patient 20 is sitting in the chair tapping his feet to the music. He has taken out a large
24 hessian shopping bag out of his cabinet and is sorting through the contents. There is a
25 lot of paperwork in it which he is reading through closely and sorting.

26 Opposite, patient 17 looks very uncomfortable. He is sitting with two pillows
27 behind his back but has slipped down the chair. His head is in his hands and he
28 suddenly looks in pain. He hasn't touched his tea, and is talking to himself. The junior
29 medic was aware that 17 was not comfortable, and it had looked like she was going to
30 get some advice, but she hasn't come back. 18 drinks his tea and looks at a wool
31 twiddle mitt sleeve, puts it down, and dozes. 19 has finished all his coffee and
32 manages to put the cup down on the trolley.

1 Everyone is tapping their feet or wiggling their toes to the music, or singing
2 quietly to it, when a student nurse, who is working at the computer station in the
3 corridor outside the room, comes in. She has a strong purposeful stride and looks
4 irritated as she switches the music off. It feels like a jolt to the room. She turns and
5 looks at me and says, 'Sorry were you listening to it?' I tell her that I think these
6 gentlemen were listening to it.

7 She suddenly looks very startled and surprised and looks at the men in the
8 room for the first time. They have all stopped tapping their toes and stopped singing
9 along. She turns it back on but asks me if she can turn it down. She leaves and goes
10 back to her paperwork outside. Once it is turned back on everyone starts tapping
11 their toes again. The music plays on: 'There'll be bluebirds over the white cliffs of
12 Dover, just you wait and see...' [Site 3 day 3]

13
14 The music was played by staff to help combat the drab and unstimulating environment of this
15 hospital ward for the patients, the very people the ward is meant to serve. Yet for this
16 member of ward staff the music was perceived as a nuisance, the men for whom the music
17 was playing seemingly did not register to her awareness. Only an individual of 'higher' status,
18 the researcher, sitting at the end of this room was visible to her. This example illustrates the
19 general question of the visibility or otherwise of patients. Focusing on our immediate topic,
20 there may be complex pathways through which clothing may impact upon how patients living
21 with dementia are perceived, and upon their self-perception.

22 23 **Clothing and identity**

24
25 On these wards, we also observed how important familiar aspects of appearance were to
26 relatives. Family members may be distressed if they find the person they knew so well,
27 looking markedly different. In the example below, a mother and two adult daughters visit the
28 father of the family, who is not visible to them as the person they were so familiar with. His
29 is not wearing his glasses, which are missing, and his daughters find this very difficult. Even
30 though he looks very different following his admission - he has lost a large amount of weight
31 and has sunken cheekbones, and his skin has taken on a darker hue – it is his glasses which
32 are a key concern for the family in their recognition of their father:

1
2 As I enter the corridor to go back to the ward, I meet the wife and daughter of the
3 patient in bed 2 in the hall and walk with them back to the ward. Their father looks very
4 frail, his head is back, and his face is immobile, his eyes are closed, and his mouth is
5 open. His skin looks darker than before, and his cheekbones and eye sockets are
6 extremely prominent from weight loss. 'I am like a bird I want to fly away...' plays softly
7 in the radio in the bay. I sit with them for a bit and we chat - his wife holds his hand as
8 we talk. His wife has to take two busses to get to the hospital and we talk about the
9 potential care home they expect her husband will be discharged to. They hope it will be
10 close because she does not drive. He isn't wearing his glasses and his daughter tells me
11 that they can't find them. We look in the bedside cabinet. She has never seen her dad
12 without his glasses: 'He doesn't look like my dad without his glasses' [Site 2 day 15].
13

14 It was often these small aspects of personal clothing and grooming that prompted powerful
15 responses from visiting family members. Missing glasses and missing teeth were notable in
16 this regard (and with the follow up visits from the relatives of discharged patients trying to
17 retrieve these now lost objects). The location of these possessions, which could have a
18 medical purpose in the case of glasses, dental prosthetics, hearing aids, or accessories which
19 contained personal and important aspects of a patient's identity, such as wallets or keys, and
20 particularly, for female patients, handbags, could be a prominent source of distress for
21 individuals. These accessories to personal clothing were notable on these wards not only by
22 their everyday absence, hidden away in bedside cupboards or simply not brought in with the
23 patient at admission, but by the frequency with which patients requested and called out for
24 them or tried to look for them, often in repetitive cycles that indicated their underlying
25 anxiety about these belongings, but which would become invisible to staff, becoming an
26 everyday background intrusion to the work of the wards.
27

28 When considering the visibility and recognition of individual persons, missing glasses,
29 especially glasses for distance vision, have a particular significance, for without them, a
30 person may be less able to recognise and interact visually with others. Their presence
31 facilitates the subject of the gaze, in gazing back, and hence helps to ground meaningful and

reciprocal relationships of recognition. This may be one factor behind the distress of relatives in finding their loved ones' glasses to be absent.

Clothing as a source of distress

Across all sites, we observed patients living with dementia who exhibited obvious distress at aspects of their institutional apparel and at the absence of their own personal clothing. Some older patients were clearly able to verbalise their understandings of the impacts of wearing institutional clothing. One patient remarked to a nurse of her hospital blue tracksuit: 'I look like an Olympian or Wentworth prison in this outfit! The latter I expect...' The staff laughed as they walked her out of the bay [site 3 day 1].

Institutional clothing may be a source of distress to patients, although they may be unable to express this verbally. Kontos has shown how people living with dementia may retain an awareness at a bodily level of the demands of etiquette.²⁰ Likewise, in our study, a man living with dementia, wearing a very large institutional pyjama top, which had no collar and a very low V neck, continually tried to pull it up to cover his chest. The neckline was particularly low, because the pyjamas were far too large for him. He continued to fiddle with his very low-necked top even when his lunch tray was placed in front of him. He clearly felt very uncomfortable with such clothing. He continued to use one hand to try to pull it up to cover his exposed chest, during and after the meal was finished [site 3 day 5].

For some patients, the communication of this distress in relation to clothing may be liable to misinterpretation and may have further impacts upon how they are viewed within the ward. Here, a patient living with dementia recently admitted to this ward became tearful and upset after having a shower. She had no fresh clothes, and so the team had provided her with a pink hospital gown to wear.

'I want my trousers, where is my bra, I've got no bra on.' It is clear she doesn't feel right without her own clothes on. The one-to-one healthcare assistant assigned to this patient tells her, 'Your bra is dirty, do you want to wear that?' She replies, 'No I want a clean one. Where are my trousers? I want them, I've lost them.' The healthcare

1 assistant repeats the explanation that her clothes are dirty, and asks her, 'Do you want
2 your dirty ones?' She is very teary 'No, I want my clean ones.' The carer again explains
3 that they are dirty.

4 The cleaner who always works in the ward arrives to clean the floor and sweeps
5 around the patient as she sits in her chair, and as he does this, he says 'Hello' to her.
6 She is very teary and explains that she has lost her clothes. The cleaner listens
7 sympathetically as she continues 'I am all confused. I have lost my clothes. I am all
8 confused. How am I going to go to the shops with no clothes on!' [site 5 day 5]

9
10 This person experienced significant distress because of her absent clothes, but this would
11 often be simply attributed to confusion, seen as a feature of her dementia; this then may
12 solidify staff perceptions of her condition. However, we need to consider that rather than her
13 condition (her diagnosis of dementia) causing distress about clothing, the direction of
14 causation may be the reverse: the absence of her own familiar clothing contributes
15 significantly to her distress and disorientation. Others have argued that people with limited
16 verbal capacity and limited cognitive comprehension will have a direct appreciation of the
17 grounding familiarity of wearing their own clothes, which give a bodily felt notion of comfort
18 and familiarity^{18,47} Familiar clothing may then be an essential prop to anchor the wearer
19 within a recognisable social and meaningful space. To simply see clothing from a task-
20 oriented point of view, as fulfilling a simply mechanical function, and that all clothing,
21 whether personal or institutional have the same value and role, might be to interpret the
22 desire to wear familiar clothing as an 'optional extra'. However, for those patients most at
23 risk of disorientation and distress within an unfamiliar environment, it could be a valuable
24 necessity.

25 26 **Personal grooming and social status**

27
28 Including in our consideration of clothing, we observed other aspects of the role of personal
29 grooming. Personal grooming was notable by its absence beyond the necessary cleaning
30 required for reasons of immediate hygiene and clinical need (such as the prevention of
31 pressure ulcers). Older patients, and particular those living with dementia who were unable
32 to carry out "self-care" independently and were not able to request support with personal

grooming, could, over their admission, become visibly unkempt and scruffy, hair could be left unwashed, uncombed and unstyled, while men could become hirsute through a lack of shaving. The simple act of a visitor dressing and grooming a patient as they prepared for discharge could transform their appearance and leave that patient looking more alert, appear to having increased capacity, than when sitting ungroomed in their bed or bedside chair.

It is important to consider the impact of appearance and of personal care in the context of an acute ward. Kontos' work examining life in a care home, referred to earlier, noted that people living with dementia may be acutely aware of transgressions in grooming and appearance, and noted many acts of self-care with personal appearance, such as stopping to apply lipstick, and conformity with high standards of table manners; clothing, etiquette and personal grooming are important indicators of social class and hence an aspect of belonging and identity, and of how an individual relates to a wider group. In Kontos' findings, these rituals and standards of appearance were also observed in negative reactions, such as expressions of disgust, towards those residents who breached these standards. Hence, even in cases where an individual may be assessed as having considerable cognitive impairment, the importance of personal appearance must not be overlooked.

For some patients within these wards, routine practices of everyday care at the bedside can increase the potential to influence whether they feel and appear socially acceptable. The delivery of routine timetabled care at the bedside can impact on people's appearance in ways that may mark them out as failing to achieve accepted standards of embodied personhood. The task-oriented timetabling of mealtimes may have significance. It was a typical observed feature of this routine, when a mealtime has ended, that people living with dementia were left with visible signs and features of the mealtime through spillages on faces, clothes, bed sheets and bedsides, that leave them at risk of being assessed as less socially acceptable and marked as having reduced independence. For example, a volunteer attempts to "feed" a person living with dementia, when she gives up and leave the bedside (this woman living with dementia has resisted her attempts and explicitly says "no"), remnants of the food is left spread around her mouth (site E). In a different ward, the mealtime has ended, yet a large white plastic bib to prevent food spillages remains attached around the neck of a person living with dementia who is unable to remove it (site X).

1

2 Of note, an adult would not normally wear a white plastic bib at home or in a restaurant; it
3 signifies a task-based apparel that is demeaning to an individual's social status. This example
4 also contrasts poignantly with examples from Kontos' work²⁰, such as that of a lady who had
5 little or no ability to verbalise, but who nonetheless would routinely take her pearl necklace
6 out from under her bib at mealtimes, showing she retained an acute awareness of her own
7 appearance and the 'right' way to display this symbol of individuality, femininity, and status.
8 Likewise, Kontos gives the example of a resident who at mealtimes 'placed her hand on her
9 chest, to prevent her blouse from touching the food as she leaned over her plate'.²⁰

10

11 Patients who are less robust, who have cognitive impairments, who may be liable to
12 disorientation, and whose agency and personhood are most vulnerable, are thus those for
13 whom appropriate and familiar clothing may be most advantageous. However, we found the
14 'Matthew Effect' to be frequently in operation: to those who have the least, even that which
15 they have will be taken away.⁴⁸ Although there may be institutional and organisational
16 rationales for putting a plastic cover over a patient, leaving it on for an extended period
17 following a meal may act as a marker of dehumanising loss of social status. By being able to
18 maintain familiar clothing and adornment to visually display social standing and identity, a
19 person living with dementia may maintain a continuity of selfhood.

20

21 However, it is also possible that dressing and grooming an older person may itself be a task-
22 oriented institutional activity in certain contexts, as discussed by Lee-Treweek⁴⁹ in the
23 context of a nursing home preparing residents for 'lounge view' where visitors would see
24 them, using residents to 'create a visual product for others' sometimes to the detriment of
25 residents' needs. Our observations regarding the importance of patient appearance must
26 therefore be considered as part of the care of the whole person and a significant feature of
27 the institutional culture.

28

Patient status and appearance

Within these wards, a new grouping of class could become imposed upon patients. We understand class not simply as socio-economic class but as an indicator of the strata of local social organisation to which an individual belongs. Those in the lowest classes may have limited opportunities to participate in society, and we observed the ways in which this applied to the people living with dementia within these acute wards. The differential impact of clothing as signifiers of social status has also been observed in a comparison of the white coat and the patient gown.⁴ It has been argued that while these both may help to mask individuality, they have quite different effects upon social status on a ward. One might say that the white coat increases visibility as a person of standing and the attribution of agency, the patient gown diminishes both of these. (Within these wards, although white coats were not to be found, the dress code of medical staff did make them stand out. For male doctors, for example, the uniform rarely strayed beyond chinos paired with a blue oxford button down shirt, sleeves rolled up, while women wore a wider range of smart casual office wear). Likewise, we observed that the same arrangement of attire could be attributed to entirely different meanings for older patients with or without dementia.

Removal of clothes and exposure

Within these wards we observed high levels of behaviour perceived by ward staff as people living with dementia displaying 'resistance' to care.⁵⁰ This included 'resistance' towards institutional clothing. This could include pulling up or removing hospital gowns, removing institutional pyjama trousers or pulling up gowns, and standing with gowns untied and exposed at the back (although this last example is an unavoidable design feature of the clothing itself). Importantly, the removal of clothing was limited to institutional gowns and pyjamas and we did not see any patients removing their own clothing. This also included the removal of institutional bedding, with instances of patients pulling or kicking sheets from their bed. These acts could and was often interpreted by ward staff as a patient's 'resistance' to care. There was some variation in this interpretation, however, when an individual patient response to their institutional clothing and bedding was repeated during a shift, it was more likely to be conceived by the ward team as a form of resistance to their care, and responded to by the replacement and reinforcement of the clothing and bedding to re-cover the person.

1
2 The removal of gowns, pyjamas, and bedsheets often resulted in a patient exposing their
3 genitalia or continence products (continence pads could be visible as a large diaper or nappy
4 or a pad visibly held in place by transparent net pants), and as such, was disruptive to the
5 norms and highly visible to staff and other visitor to these wards. Notably, unlike other
6 behaviours considered by staff to be disruptive or inappropriate within these wards such as
7 shouting or crying out, the removal of bedsheets and the subsequent bodily exposure would
8 always be immediately corrected, the sheet replaced, and the patient covered by either the
9 nurse or health care assistant. The act of removal was typically interpreted by ward staff as
10 representing a feature of the person's dementia and staff responses were framed as an issue
11 of patient dignity, or the dignity and embarrassment of other patients and visitors to the
12 ward. However, such responses to removal could lead to further cycles of removal and
13 replacement, leading to an escalation of distress in the person. This was important, because
14 the recording of 'refusal of care', or presumed 'confusion' associated with this, could have
15 significant impacts on the care and discharge pathways available and prescribed for the
16 individual patient.

17
18 Consider the case of a woman living with dementia who is 90 years old (patient 1), in the
19 example below. Despite having no immediate medical needs, she has been admitted to the
20 medical assessment unit from a care home (following her husband's stroke, he could no
21 longer care for her). Across the previous evening and morning shift she was shouting,
22 refusing all food and care, and has received assistance from the specialist Dementia Care
23 Worker. However, during this shift she has become calmer following a visit from her husband
24 earlier in the day, has since eaten and requested drinks. Her care home would not readmit
25 her, which meant she was not able to be discharged from the unit (an overflow unit due to a
26 high number of admissions to the Emergency Department during a patch of exceptionally hot
27 weather) until alternative arrangements could be made by social services.

28
29 During our observations, she remains calm for the first two hours. When she does talk she is
30 very loud and high pitched, but this is normal for her and not a sign of distress. For staff
31 working on this bay their attention is elsewhere, because of the other six patients on the

unit, one is “on suicide watch” and another is “refusing their medication” (but does not have a diagnosis of dementia). At 15:10 patient 1 begins to remove her sheets:

15:10: The unit seems chaotic today. Patient 1 has begun to loudly drum her fingers on the tray table. She still has not been brought more milk, which she requested from the HCA an hour earlier. The bay that patient 1 is admitted to is a temporary overflow unit and as a result staff do not know where things are. 1 has moved her sheets off her legs, her bare knees peeking out over the top of piled sheets.

15:15: The nurse in charge says, ‘Hello,’ when she walks past 1’s bed. 1 looks across and smiles back at her. The nurse in charge explains to her that she needs to shuffle up the bed. 1 asks the nurse about her husband. The nurse reminds 1 that her husband was there this morning and that he is coming back tomorrow. 1 says that he hasn’t been and she does not believe the nurse.

15:25: I overhear the nurse in charge question, under her breath to herself, ‘Why 1 has been left on the unit?’ 1 has started asking for somebody to come and see her. The nurse in charge tells 1 that she needs to do some jobs first and then will come and talk to her.

15:30: 1 has once again kicked her sheets off of her legs. A social worker comes onto the unit. 1 shouts, ‘Excuse me’ to her. The social worker replies, ‘Sorry I’m not staff, I don’t work here’ and leaves the bay.

15:40: 1 keeps kicking sheets off her bed, otherwise the unit is quiet. She now whimpers whenever anyone passes her bed, which is whenever anyone comes through the unit’s door. 1 is the only elderly patient on the unit. Again, the nurse in charge is heard sympathizing that this is not the right place for her.

16:30: A doctor approaches 1, tells her that she is on her list of people to say hello to, she is quite friendly. 1 tells her that she has been here for 3 days, (the rest is inaudible because of pitch). The doctor tries to cover 1 up, raising her bed sheet back over the bed, but 1 loudly refuses this. The doctor responds by ending the interaction, ‘See you later’, and leaves the unit.

16:40: 1 attempts to talk to the new nurse assigned to the unit. She goes over to 1 and says, ‘What’s up my darling?’ It’s hard to follow 1 now as she sounds very upset. The RN’s first instinct, like with the doctor and the nurse in charge, is to cover up 1s legs

1 with her bed sheet. When 1 reacts to this she talks to her and they agree to cover up
2 her knees. 1 is talking about how her husband won't come and visit her, and still
3 sounds really upset about this. [Site 3, Day 13]
4

5 Of note is that between days 6 and 15 at this site, observed over a particularly warm
6 summer, this unit was uncomfortably hot and stuffy. The need to be uncovered could be
7 viewed as a reasonable response, and in fact was considered acceptable for patients without
8 a classification of dementia, provided they were otherwise clothed, such as the hospital
9 gown patient 1 was wearing. This is an example of an aspect of care where the choice and
10 autonomy granted to patients assessed as having (or assumed to have) cognitive capacity is
11 not available to people who are considered to have impaired cognitive capacity (a diagnosis
12 of dementia) and carries the additional moral judgements of the appropriateness of
13 behaviour and bodily exposure. In the example given above, the actions were linked to the
14 patient's resistance to their admission to the hospital, driven by her desire to return home
15 and to be with her husband. Throughout observations over this 10 day period, patients
16 perceived by staff as rational agents were allowed to strip down their bedding for comfort,
17 whereas patients living with dementia who responded in this way were often viewed by staff
18 as "undressing", which would be interpreted as a feature of their condition, to be challenged
19 and corrected by staff.
20

21 Note how the same visual data triggered opposing interpretations of personal autonomy. Just
22 as in the example above where distress over loss of familiar clothing may be interpreted as
23 an aspect of confusion, yet lead to, or exacerbate, distress and disorientation; so 'deviant'
24 bedding may be interpreted, for some patients only, in ways that solidify notions of lack of
25 agency and confusion, is another example of the Matthew Effect⁴⁸ at work through the
26 organisational expectations of the clothed appearance of patients.
27

28 Within wards it is not unusual to see patients, especially those with a diagnosis of dementia
29 or cognitive impairment, walking in the corridor inadvertently in some state of undress,
30 typically exposed from behind by their hospital gowns. This exposure in itself is of course, an
31 intrinsic functional feature of the design of the flimsy back-opening institutional clothing the
32 patient has been placed in. This task-based clothing does not even fulfil this basic function

1 very adequately. However, this inadvertent exposure could often be interpreted as an overt
2 act of resistance to the ward and towards staff, especially when it led to exposed genitalia or
3 continence products (pads or nappies).

4
5 We speculate that the interpretation of resistance may be triggered by the visual prompt of
6 disarrayed clothing and the meanings assumed to follow, where lack of decorum in attire is
7 interpreted as indicating more general behavioural incompetence, cognitive impairment,
8 and/or standing outside the social order.

11 Discussion

13 Previous studies examining the significance of the visual, particularly Twigg and Buse's
14 work¹⁶⁻¹⁹ exploring the materialities of appearance, emphasises its key role in self-
15 presentation, visibility, dignity and autonomy for older people and especially those living with
16 dementia in care home settings. Similarly care home studies have demonstrated that
17 institutional clothing, designed to facilitate task-based care, can be potentially dehumanising
18 or and distressing^{25,26}. Our findings resonate with this work, but find that for people living
19 with dementia within a key site of care, the acute ward, the impact of institutional clothing
20 on the individual patient living with dementia, is poorly recognised, but is significant for the
21 quality and humanity of their care.

23 Our ethnographic approach enabled the researchers to observe the organisation and delivery
24 of task-oriented fast paced nature of the work of the ward and bedside care. Nonetheless it
25 should also be emphasised the instances in which staff such as Healthcare Assistants and
26 specialist dementia staff within these wards took time to take note of personal appearance
27 and physical caring for patients and how important this can be for overall wellbeing. None of
28 our observations should be read as critical of any individual staff, but reflects longstanding
29 institutional cultures.

31 Our previous work has examined how readily a person living with dementia within a hospital
32 wards is vulnerable to dehumanisation,⁵¹ and to their behaviour within these wards being

1 interpreted as a feature of their condition, rather than a response to the ways in which
2 timetabled care is delivered at their bedside⁵⁰. We have also examined the ways in which
3 visual stimuli within these wards in the form of signs and symbols indicating a diagnosis of
4 dementia may inadvertently focus attention away from the individual patient and may incline
5 towards simplified and inaccurate categorisation of both needs and the diagnostic category
6 of dementia.⁵²

7
8 Our work supports the analysis of the two forms of attention arising from McGilchrist's
9 work.¹⁰ The institutional culture of the wards produces an organisational task-based technical
10 attention, which we found appeared to compete with and reduce the opportunity for ward
11 staff to seek a finer emotional attunement to the person they are caring for and their needs.
12 Focus on efficiency, pace, and record keeping that measures individual task completion
13 within a timetable of care may worsen all these effects; indeed other work has shown that in
14 some contexts, attention to visual appearance may itself be little more than a 'task' to
15 achieve.⁴⁹ McGilchrist makes clear, and we agree, that both forms of attention are vital, but
16 more needs to be done to enable staff to find a balance.

17
18 Previous work has shown how important appearance is to older people, and to people living
19 with dementia in particular, both in terms of how they are perceived by others, but also how
20 for this group, people living with dementia, clothing and personal grooming may act as a
21 particularly important anchor into a familiar social world. These twin aspects of clothing and
22 appearance – self-perception and perception by others - may be especially important in the
23 fast paced context of an acute ward environment, where patients living with dementia may
24 be struggling with the impacts of an additional acute medical condition within in a highly
25 timetabled and regimented and unfamiliar environment of the ward, and where staff
26 perceptions of them may feed into clinical assessments of their condition and subsequent
27 treatment and discharge pathways. We have seen above, for instance, how behaviour in
28 relation to appearance may be seen as 'resisting care' in one group of patients, but as the
29 natural expression of personal preference in patients viewed as being without cognitive
30 impairments. Likewise, personal grooming might impact favourably upon a patient's
31 alertness, visibility and status within the ward.

32

Prior work has demonstrated the importance of the medical gaze for the perceptions of the patient. Other work has also shown how older people, and in particular people living with dementia, may be thought to be beyond concern for appearance, yet this does not accurately reflect the importance of appearance we found for this patient group. Indeed we argue that our work, along with the work of others such as Kontos^{20,21}, shows that if anything, visual appearance is especially important for people living with dementia particularly within clinical settings. In considering the task of washing the patient, Pols⁵³ considered 'dignitas' in terms of aesthetic values, in comparison to humanitas conceived as citizen values of equality between persons. Attention to dignitas in the form of appearance, may be a way of facilitating the treatment by others of a person with humanitas, and helping to realise dignity of patients.

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