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Visual identifiers for people with dementia in hospitals: a qualitative study to unravel mechanisms of action for improving quality of care

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ABSTRACT

Background Hospitalised people with dementia (PwD) experience worse care and more patient safety incidents than non-dementia patients. Visual identifiers are commonly used to identify patients who have a diagnosis of dementia, with the aim of promoting more personalised care. However, little is known about how they work in practice, nor about the potential unintended consequences that might arise from their use. We aim to identify the mechanisms through which visual identifiers could support good care for PwD, how and why their use may have negative consequences and the conditions for their effective use.

Methods We conducted interviews with 21 dementia leads and healthcare professionals, 19 carers and two PwD, and produced case studies of visual identification systems in four UK acute hospital trusts between 2019 and 2021. Analysis drew on the concept of classification to identify and explore mechanisms of action.

Results We identified four mechanisms through which visual identifiers could help towards providing good care for PwD: enabling coordination of care at organisational level; signalling eligibility for dementia-specific interventions; informing prioritisation of resources on wards; and acting as a quick reference cue for staff. But identifier effectiveness could be undermined by: lack of standardisation and consistency; a lack of closely coupled information about individual needs; and stigma associated with a dementia diagnosis. Identifier effectiveness was dependent on their implementation being supported through staff training, resources directed and efforts to develop a supportive culture for caring for this patient group.

Conclusion Our research highlights the potential mechanisms of action of visual identifiers and their possible negative consequences. Optimising the use of identifiers requires consensus on the rules of classification and the symbols used, and closely coupled patient information. Organisations need to provide support, offer the right resources and training and engage meaningfully with carers and patients about the use of identifiers.

INTRODUCTION

Approximately a quarter of hospital beds in the UK are occupied by someone

WHAT IS ALREADY KNOWN ON THIS TOPIC

⇒ Hospitalised patients with dementia often experience poor care. Visual identifiers for this group are designed to increase awareness of a person's dementia diagnosis and are already in routine use across hospitals in the UK and beyond. Although they can help staff identify patients with additional needs, their use has also been criticised for failing to bring about improvements and even contributing to poor care.

WHAT THIS STUDY ADDS

⇒ Using the concept of classification, and based on interviews with staff and people with dementia (PwD) and their relatives, we describe the mechanisms through which visual identifiers could help improve care for PwD, and how negative consequences can arise. We need to understand the mechanisms of effect of visual identifiers for PwD: how they can work to improve care, and how, why and under what circumstances their use can lead to negative unintended consequences. Without this understanding there is a risk that this widely used intervention will have a limited or even negative impact on the care of PwD in practice.

HOW THIS STUDY MIGHT AFFECT RESEARCH, PRACTICE OR POLICY

⇒ Pairing visual identifiers with well-designed personalised information documents, ensuring the right resources and training for staff and seeking genuine engagement with relatives and carers are critical for their effective use.

living with dementia.[1] Evidence suggests that people with dementia (PwD) experience longer stays, higher readmissions, greater numbers of patient safety incidents and a higher risk of mortality than those without dementia.[2–6] PwD have specific additional needs when in hospital, which are not always met, including needs related to communication, nutrition, continence and managing confusion and distress.[7–9] Importantly, PwD have a need for genuine connections and empathetic communications with staff to feel safe.[10] Previous studies also highlight many missed opportunities in providing person-centred care for PwD in acute care settings.[11]

To address these concerns, many hospitals within the UK, and in other countries including Australia and the USA,[12–15] have introduced visual identifiers for PwD. These typically take the form of symbols—such as a butterfly—added to wristbands or displayed on bedside signs with the aim of raising staff awareness that a patient may have additional needs. Identifiers are often used in combination with other interventions, such as staff training on providing care to PwD in an effort to promote an approach that better meets the needs of PwD and supports the delivery of person-centred care. While identifiers are hypothesised to have value for improving the care of PwD in hospitals, potential problems with their use have also been raised. These include risks of obscuring the person behind the diagnosis, resulting in less personalised care, problems with misclassification of patients[16] and concerns about the consistency and reliability of their use.[17]

Over 90% of hospitals in England have identification systems in place for PwD.[18 19] Despite their widespread use in practice, none of these schemes have been fully evaluated.[20] Given that visual identifiers for PwD are in routine use across hospitals in the UK and beyond, there is a pressing need to understand their potential mechanisms of action: how they function to improve care. It is also important to pay attention to their potential 'dark logic'; to consider how, why and under what circumstances their use might lead to negative unintended consequences, either on the outcomes of interest ('paradoxical effects') or other outcomes ('harmful externalities').[21] This understanding will be valuable in informing decisions about whether and how to use identifiers and in what form, and in developing approaches to counter possible harms from their use.

Based on a qualitative study with health professionals, PwD and their carers, we analyse mechanisms through which visual identifiers work in practice, what problems they can address and when and how they might generate negative consequences. This understanding will inform future efforts to use identifiers more effectively to support good care for PwD.

METHODS

As part of a broader programme of research into the use of visual identification systems for PwD in hospital,[20 22] we conducted a qualitative study involving in-depth case studies and interviews with health professionals, PwD and their carers between 2019 and 2021. We selected four acute care sites as case studies: two large and two smaller hospitals (based on the number of beds) in different regions of England. In consultation with experts in dementia care, sites were selected to include hospitals using a range of identifiers (including the national butterfly scheme[17] and locally developed identifiers) and with varying levels of performance in implementing their dementia strategies. In each of the four sites, we interviewed the dementia lead or senior dementia nurse about their organisation's approach to quality of care for PwD. We gathered documentation including dementia strategies and any dementia-related information displayed in each site. We also recruited front-line healthcare professionals with experience of working with PwD across diverse roles within the case study sites (three to seven per site). An additional five health professionals who worked with PwD were recruited through their willingness to take part in an interview after completing a national survey that formed part of the wider research programme[20] to gain insight into practices beyond the four case study hospitals. Interviews with health professionals explored experiences of providing hospital care for PwD and how visual identifiers and related interventions worked in practice.

We also conducted interviews with PwD and their relatives. Participants were recruited through the 'Join Dementia Research' network[23] and via social media. Interviews explored experiences of hospital care, and views on visual identifiers and related interventions. Patient and carer topic guides were piloted with a person with dementia and a carer (see online supplemental materials 1 and 2 for topic guides).

Due to the COVID-19 pandemic, all interviews were conducted by telephone or online, with written informed consent. All interviews were conducted by an experienced non-clinical qualitative researcher (ES), and lasted between 30 and 90 min. Interviewing continued until no new themes were identified. Interviews were audio recorded, transcribed verbatim and analysed using a thematic analysis approach.[24] ES conducted initial open coding of transcripts by hand. This coding was inductive and included the way that identifiers could impact both positively and negatively on care quality. This informed the development of a coding framework, where codes were grouped into higher order themes (see coding frame in online supplemental material 3). This was refined and revised in discussion with CT, and used to code subsequent transcripts using NVivo V.12 software. We used compiled narrative case studies for each site. In each case, we mapped out the type of tools and approaches

used to identify and support PwD. We interrogated the themes and case studies to explore the practices and meanings associated with the use of visual identifiers, and perceptions of their impact on quality of care for PwD. This was undertaken by comparing and contrasting the views of healthcare professionals, relatives of those with dementia and those living with dementia, and the documentation from each site. In particular, we contrasted the 'official' reports of how identifiers should be used in each site with what individuals told us about how they worked in practice and the consequences of their use.

RESULTS

Twenty-one healthcare professionals, 19 relatives of PwD and two people living with dementia took part in the interviews. Quotation identifiers explain the type of person interviewed. For health professionals, identifiers also show either the case study they were from or that they were recruited from the survey. In this section, we first present findings on the case studies of how visual identifiers were being used in practice. We then articulate several 'mechanisms of action' through which the use of such identifiers could lead to better care and outcomes for PwD. Finally, we consider some of the potential failures and unintended consequences of such tools.

Visual identifiers: classifying patients and signalling category membership

The application of a visual identifier acted as a visible classification system[25]—identifying people as belonging to a specific group or category, that of 'people with dementia' (and/or with suspected dementia or delirium). Visual identifiers used across sites were multiple and varied, and included alerts on hospital electronic systems, stickers and magnets on notes and whiteboards, and bedside signs and wristbands displaying a symbol (eg, a forget-me-not flower or butterfly). Table 1, based on case study analysis of the four sites drawing on key documents and interviews with dementia leads, summarises the variation in use of identifiers across the sites.

Mechanisms of action: how visual identifiers could support good care

We identified several mechanisms through which visual identifiers could positively support the delivery of good care for PwD: through enabling care coordination at organisational level, signalling eligibility for dementia-specific initiatives, allowing allocation of resources at ward level and acting as a quick reference cue to prompt assessment of needs. For detailed quotes see table 2.

The ability to mark people as belonging to the category 'person with dementia' opened up possibilities to *improve coordination and delivery of care at organisational level*. For example, flags on electronic systems

Table 1 Variation in identifiers used across the case study sites

Symbol used	
Butterfly for confirmed dementia diagnosis, outlined butterfly for suspected dementia/delirium	Site 1 (red) Site 3 (blue—part of national scheme)[17]
Forget-me not flower for confirmed dementia diagnosis	Site 2 Site 4
Sunflower for 'Hidden disabilities'	Site 3
Chrysanthemum for delirium	Site 4
Location of identifier	
Wristband	Site 1 (identifier on admissions wristband) Site 4 (additional coloured wristband for dementia/delirium)
Symbol on bedside board/poster by the bed	Site 1 (tick next to symbol at bedside) Site 2 (flower drawn in pen) Site 3 (laminated butterfly poster) Site 4 (tick next to symbol at bedside)
Sticker in notes	Site 2 Site 3
Magnet next to patient name on whiteboard	Site 2
Identifier (flag or alert) on hospital electronic records system	Site 1 Site 2 Site 4
Consent to apply identifier	
Express consent needed	Site 3 Site 4
Opt-out/no consent needed	Site 1 Site 2
Personalised patient documents	
Booklet—'This is me', 'Reach out to me' Patient profile	Site 2 Site 3 Site 4 Site 1
Poster at bedside—'What's important to me'	Site 4

could help identify and locate PwD within the hospital, which could then help to support the coordination of their care pathways, including avoiding unnecessary moves around the hospital. Identifiers also helped with efforts to audit, monitor and improve the quality of care for this patient group as a whole.

Identifiers on wristbands and patient documents also played a role in the delivery of hospital-wide initiatives for enhanced care for this patient group—such as meaningful activity coordinators (site 2), dementia volunteer support, fast tracking through X-ray pathways or additional support for nutritional or other needs. *Identifiers acted as a marker that signalled their eligibility for these dementia-specific initiatives.* Visual identifiers also acted to alert individual ward staff interacting with a patient, at the point of care, that a patient had dementia. This was perceived to have value, by both staff and relatives, in prompting

Table 2 Mechanisms of action: how visual identifiers could support good care

Mechanism	Quote
Enabling or supporting coordination and improvement at organisation level	*[With] the alert system, the operations centre and patient flow, particularly the hospital at night team, could actually see where our patients with dementia were. And it's part of the trust policy … in accordance with National Audit of Dementia recommendations – … trying to now reduce those transfers around the hospital*. (Dementia lead, 001, Survey)
Signalling eligibility for dementia-specific interventions	*Anybody who comes in to ED, who's identified through the forget-me-not scheme, is immediately assessed by the meaningful activity service*. (Executive nurse, 006, Site 2) *When someone's got dementia, they get a laminated [card] so if they've got four people in front [waiting for an x-ray], they go 'actually I'll take that one first', because that person's obviously got [dementia] and we're gonna get them, fast-track them through a bit quicker*. (Dementia lead, 07, Site 3)
Helping to prioritise resources at ward level	*I mean like I've just picked up my handover, the first patient I see, I don't have to read anything and I can see that he's got dementia so even though I don't know anything more … I'm just looking at my identifiers. And I can see that this patient is probably going to need quite a lot of assistance that day*. (Senior nurse, 002, Site 1)
Providing quick reference cue to additional needs of patient	*For these kind of people, we know that we have to … have more patience with them, to know about them, what they like, what they dislike. Because they can feel very lost, they don't know us, they are in a very strange environment, with different people every day, so this will affect their behaviour and their eating, drinking*. (Senior nurse, 03, Site 1) *[A wristband] is just a simple thing, you know, and you put it on, and the world just takes a step back and thinks, 'Oh, we might need to approach it differently. We might need to word things differently.' […] It just makes everybody just a little bit kinder*. (Daughter, 13)

ward staff to consider the needs and limitations associated with the membership of the category 'person with dementia'. While this often meant drawing on generalised knowledge about dementia, rather than information about the individual patient, being able to identify someone as belonging to this category had the potential to improve interactions and quality of care. It could help staff to make sense of a person's behaviour in the context of a dementia diagnosis, tailor their communication approach to avoid distress and take into account likely limitations in a person's memory or communication ability.

At ward level, visual identification systems were seen as particularly helpful in *enabling managers to organise and plan their resources for day-to-day care within the ward*. A visual overview of the number of patients on the ward with dementia—from the e-system, whiteboard magnets or bedside identifiers—could provide accessible information to inform assessments of availability of staff with relevant expertise and guide allocation of staff or requests for additional staffing.

By providing a quick reference cue, identifiers on wristbands also supported efforts to protect the safety of patients in this group, reflecting the particular vulnerabilities of many PwD, for example, prompting staff to consider fall risks, or enabling identification of patients who may have left their ward and become lost.

Using visual identifiers: potential failures and unintended consequences
Although visual identifiers were recognised as having the potential to improve the coordination and delivery of care for PwD, we also identified challenges with the use of tools that could undermine their effectiveness in practice, and potentially generate negative consequences. For detailed quotes see table 3.

The value of the identifier was dependent on collective understanding of its meaning and what it signified. But *we found a lack of standardisation of symbols used across different sites which undermined their value as a quick reference tool* (table 1 and table 3 for quotes), and no universal understanding of what the symbols meant across the workforce within and across sites. This lack of standardisation was perceived as particularly problematic when staff were locums or bank staff who might work at several different hospitals. The confusion that different identifiers, and ways of using them, might cause to patients and their families was also a concern. Additional resources were in place alongside visual identifiers in all hospitals we studied to provide staff with this personal information for PwD (in the form of a booklet or poster). These resources were designed to help staff better understand the interests and individual needs of a person. Staff felt, however, that personal information documents were poorly completed and used inconsistently. In addition, some accompanying personal information booklets, originally designed to be used in long-term care, were relatively detailed and dense. They focused on providing rich details about the person behind the diagnosis of dementia. Although specialist dementia staff and volunteers reported this was valuable in helping them find out more about the person, *this format did not meet the needs of clinical staff for quick and easy access to key information*. Booklets tended to be put away at the back of patients' notes or at the bedside, and clinical staff tended not to prioritise taking time to read detailed personal information documents in the context of a time-pressured environment. In contrast, posters that provided personal information 'at a glance' provided limited information for dementia specialists and volunteers, but were felt to work well as a means of communicating relevant

Table 3 Potential failures and unintended consequences of visual identifiers

Potential failure/unintended consequence	Quote
Lack of standardisation of symbols undermined their value as a quick reference cue.	*For example, if the patient comes to one hospital, and the next of kin are being told about this identifier, and then they go […] during the night to another hospital, which has completely different ones, it can be confusing. And doctors which move hospitals, benefit from [standardisation]. Because it's not something new to them. They know how to approach it. (Ward clerk, 011, Site 4)*
Inconsistencies in application of identifiers created inequalities.	*The lady I saw just now … on the Medical Assessment Unit…she'll probably end up on one of the care of the elderly wards, she'll be on The Butterfly Scheme and that's fine. But if she ends up on a medical ward…, they may or may not remember to use it. (Dementia lead, 01, Site 3)* *By not having [an identifier], they will not receive the additional support that they might [have] received, if people had known that they had got dementia. (Wife, 11)*
Lack of closely coupled information about individual needs hindered person-centred care.	*It feels like the label has to […] direct them to more information. (Daughter, 03)* *All it does is an identifier that they have [dementia]…. And then it's everything else, … what this person's like, what they need, what they're like at home, what they like to drink, how they like their tea, you know, all that sort of thing. You can't get that from a butterfly, you can't get that from … anything really other than knowing your patient. (Senior nurse, 02, Site 1)* *If people … base assumptions about the diagnosis… without finding out about the patient… Then you could, you could be at risk of decompensating them really, because you start doing things at them and for them, rather than letting them try to do things themselves and support them. (Senior dementia nurse, 018, Survey)* *You've got the Reach Out To Me [booklet] in the [patient] documentation, why have [staff] not read that and why have you not seen what he likes and what he doesn't like? […] If somebody can't see, if they haven't got their glasses, that's why they can't see. (Dementia lead, 07, Site 3)*
Signalling category membership could result in stigma and discrimination.	*I mean I just honestly can't stand the way that people judge dementia patients, it's just horrible, they just think there's nothing more you can do with them, and that's it, you just give up. (Dementia lead, 07, Site 3)* *[Staff attitude was] 'Oh well he ain't bothered because he has got dementia'! Neglect is what I would have said. (Daughter, 012)*
Effectiveness was dependent on staff training and resources.	*If I had to ask like what would be the factor that affects their care, I would say it would be the staffing. Like most of the time we won't be getting any one-to-one cover, [We had a] patient who had, who just fall because of that, because of the staffing issues. (Senior nurse, 012, Site 02)* *[Instead of saying] 'Sit down, sit down, you're high risk of falls' […] in actual fact we're doing a lot of work [to develop staff] understanding, [that] by engaging them in an activity, you know, that's going to improve their experience, make them feel more engaged, happier. (Dementia lead, 001, Survey)* *We're looking at like coping strategies with staff, how to debrief regularly with each other, how to reflect on everything. (Senior nurse, 02, Site 1)*

information about a patient to busy clinical, ward and support staff.

There were practical challenges with labelling patients, particularly in relation to the use of wristbands, bedside signs and whiteboard magnets. Across all the sites, many healthcare professionals were uncertain about whose responsibility it was to apply an identifier, and at what point in the patient's journey this should happen. Staff reported a lack of consistency about the point in the patient's journey at which they were applied and variable engagement across different types of ward. *In practice, visual identifiers were not used consistently to flag eligible patients for the additional support that they needed.* As a result of this lack of consistency, patients who should have benefited from additional dementia support could be overlooked. By default, *the lack of an identifier implicitly classified them into the 'non-dementia' category, leading to inequalities in care provision.* There were also ambiguities and differences of opinion about who was, and who should be, eligible to have a visual identifier applied (only patients with confirmed dementia, or patients with suspected dementia and delirium). *This resulted in inconsistencies across hospitals in terms of which types of patients would have access to*

the pathways and initiatives designed for patients with additional needs.

Even if appropriately applied, identifiers in and of themselves did not guarantee better care. The identifier directed attention to the dementia diagnosis, but did not provide any information about the individual person behind the diagnosis, their abilities, needs and preferences. Staff described how classifying and identifying people as belonging to the category 'person with dementia' could lead to over-reliance on assumptions based on category membership. While awareness of the dementia diagnosis could alert staff to use a more dementia-friendly approach in their communication with a patient (as described above), it could also result in staff acting on assumptions about the limitations of patients with dementia, which could disempower patients and impact negatively on their independence and functional ability. Relatives recognised the limitations to what a visual identifier on its own could achieve, *unless it was coupled with efforts to enable a more personalised response based on information about individual needs.*

Although the staff, relatives and PwD we interviewed mostly felt that identifiers were potentially of benefit (even if this benefit was not fully realised in

practice), some family members felt that their loved one would not want their diagnosis to be made visible. *The use of an identifier was seen by some as having the potential to lead to negative consequences due to negative cultural representations of dementia.* Some staff, relatives and PwD had concerns that marking patients with an identifier could result in prejudice and discrimination within the healthcare setting, if staff held negative beliefs about patients with dementia. Some relatives described their loved one experiencing discrimination in practice.

Both staff and relatives recognised that identifiers alone had limited potential to improve the care of PwD. Lack of in-depth training (particularly for bank or locum staff) on the skills and knowledge required to communicate and support PwD in hospitals, lack of local expertise in dementia and limited resources to provide the additional support required all made it more likely that an identifier would be ineffective in improving care. *The extent to which identifiers could enable better care was dependent on their use being supported through staff training, resources directed at the needs of PwD and efforts to develop a more informed and supportive culture for caring for PwD.*

DISCUSSION

Our research shows how classifying people as belonging to the 'dementia' category, and visibly signalling this category membership, could support improvements in the quality of care delivery for PwD in hospital. In particular, our participants perceived such classificatory tools as having the potential to play an important role in: enabling coordination of care at organisational level; signalling eligibility for dementia-specific interventions; informing prioritisation of resources on wards; and acting as a quick reference cue for staff interactions with patients. Provided staff have the skills and time to engage effectively with PwD, and are working within a supportive and well-resourced environment, they can use this information to tailor their interactions with patients in line with the broad needs of PwD. But such tools can fail to deliver on their promise, and potentially have negative consequences, when there is a lack of standardisation and consistency, a lack of closely coupled information about individual needs and a risk of discrimination associated with making the condition visible.

Featherstone and colleagues have been particularly critical of the use of signs and symbols for PwD in hospitals. In line with some of our findings, they argue that these 'technologies of attention' obscure the person, risk misclassification and can lead to depersonalised care.[16] A recent national survey on the use of visual identifiers[20] found drawbacks to the use of visual identifiers, such as concerns about disclosure and discrimination as well as practical challenges to their use. There is a danger, however, of arguing against the use of visual identifiers as an approach to optimising care for PwD on the basis of their potential to generate negative consequences. It is not that the principles of classification and labelling themselves are problematic—our research shows that being able to classify and mark patients as belonging to a vulnerable group with additional needs can (at least potentially) bring significant benefits in terms of optimising the organisation and delivery of care. Rather, we argue that we need instead to understand *when and why* such classification systems can generate negative consequences (their potential 'dark logic'), and consider how to mitigate against these. This is particularly important as our and others' work would seem to suggest that unintended consequences in this context are primarily on the outcomes of interest (so-called 'paradoxical effects'), meaning that there is a very real risk that care for this vulnerable group of patients is made worse rather than better. Inconsistencies in the application of, and attribution of meaning to, the marker could create confusion and inequalities in care. We recommend that, at a national level, healthcare organisations gain consensus on the rules of classification, the process of applying the marker and the symbol to be used. To overcome the risks of assumptions and depersonalised care associated with a classification system, any markers applied to patients should act as a *flag* to staff to seek out personal information, rather than merely operate as a *label* to show a patient is a member of a category.

Our findings suggest that documents such as the 'This is me' booklet, designed to provide this personal information, were not immediately accessible for busy clinical staff and were rarely consulted by the staff providing care. Bedside posters provided a more easily accessible reference point for busy hospital staff. We suggest a need for more closely coupled personalised information to be integrated with the visual identifier. Such a resource should include the key information about individual needs and preferences that is most relevant to the person's hospital care, and should be immediately accessible to all staff.

Simply implementing dementia-friendly initiatives such as visual identifiers and patient profiles without supporting staff with resources or training will fail to bring about good dementia care. The extent to which identifiers could enable better care was dependent on their use being supported through staff training, resources directed at the needs of PwD and efforts to develop a supportive culture for caring for PwD. Others have argued that dementia-friendly interventions such as visual identifiers need to be accompanied by efforts to build staff understanding of dementia, a framework for providing good dementia care and support from local change agents to bring about good care.[26] Hospitals have to provide a supportive context for good dementia care to take place, and dementia care has to be embedded in an organisational commitment to optimise the delivery of care and ensure that systems are in place to support it. There is a real need

for regular and in-depth training to enable effective responses to the classification of dementia. This training should seek to provide understanding of the common issues but also the spectrum of diversity in the group to avoid stereotyping, discrimination and stigma based on group membership. Impactful training should include input from patient and relative experiences and highly skilled facilitators.[27] It should be available for all staff, including locum and agency staff. Finally, and very importantly, organisations need to ensure the engagement of patients and their carers in terms of their attitudes towards classification and their consent to be labelled.[22] It is vital that discussions are held with relatives and patients as to the implications of being classified, having a marker applied and addressing concerns about stigma and discrimination.

Strengths and limitations

Our study included a small sample of four hospitals yet these all used a varying range of identifiers. In addition, our approach to site selection ensured we included sites with diversity in levels of engagement with their dementia strategies. Interviewees included dementia leads who were involved with the implementation of identifiers. While these staff are likely to have positive views of identifiers, we also interviewed front-line staff involved in the care of PwD to explore the realities of the way identifiers worked in day-to-day practice. We were only able to recruit two PwD to participate in interviews: we intended to recruit via in-person visits to hospitals, local groups and dementia cafes, but this was not possible due to the COVID-19 pandemic. We also were unable to undertake planned visits to hospitals to observe the use of identifiers in practice. Observation is a powerful method in uncovering the (often unconscious) gap between rhetoric and reality in dementia care,[28] and future observational research would be of value. However, we were able to produce comprehensive case studies of local practices across four hospitals by interviewing a range of staff and drawing on a range of documentation used in each site.

Characterising visual identifiers as an example of a classification system provides us with new insights into the underlying principles of their use and the mechanisms through which they might work. Classification is argued to involve segmenting the world to conduct some form of work—in this case, the intention is to delineate a population of patients who are likely to require (and are eligible for) additional support while in hospital.[25] However, as we have shown, the classificatory act in and of itself is not sufficient to deliver better care to those identified. In order to deliver meaningfully on their promise, classificatory tools such as visual identifiers need to be used in contexts which are capable of effectively delivering the work required to generate the desired outcomes of having classified.

CONCLUSION

Interviews with staff, PwD and their relatives reveal the mechanisms through which visual identifiers could play an important role in improving the quality of care for PwD. Characterising visual identifiers in terms of classification can help in understanding the mechanisms through which they can generate positive or negative consequences, as well as informing efforts to optimise their effectiveness in practice.

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Interview Topic Guide

DA VINCI: What affects the quality of care for people with dementia in hospitals and where can a visual system help? Health professionals' views

1. Welcome and introduction

Seek consent to continue and to audio-record the interview. Let participant know that no personal identifiable data will be recorded and an ID number will be allocated to them

2. Introductory questions

To start could you tell me about your current role? How long have you held that post for?

Could you tell me a bit about your experience in working with people with dementia? (if not already mentioned).

3. Visual identification system in your organisation

We are interested in the dementia care approach in your organisation and in particular the visual identifier you use (e.g. butterfly, flower, wristband). Can you tell me more about the identifier? What does it involve and how does it work? *Probe for context: Where used, by whom? At what point in the patient's journey?*

How are patients and relatives involved in decisions about using identifiers? How do you get consent?

So what else does your visual identification system involve to help in providing good care to people with dementia (e.g. guidelines, training, policy…)? How important do you think these are and why?

What do you feel about the visual identifier you use in your organisation, does it work well? Why? Are there any limitations?

4. Challenges in providing high quality care for people with dementia

What do you see as the main challenges in providing high quality care for people with dementia in hospital? Why do you think these problems and challenges are difficult to overcome?

In your experience, does using a visual identification system help to address some of these challenges? In what ways (*examples from their experience)*?

In your experience, are there any challenges that a visual identification system doesn't help address? If so what are they?

I'd like to discuss in a bit more detail now your views on visual identifiers, what you see as the benefits and tensions, and how you think they would work in an ideal world.

5. Views on the benefits and challenges of visual identifiers

What do you see as the main purpose of using visual identification systems? Why is this important?

Interview Topic Guide

Who do you think needs to know that a patient has dementia, at what point and why?

What benefits do you think visual identification systems have for patients, relatives, staff, your organisation?

Do you think using visual identifiers has any harms or negative consequences?

- for the patient
    - o Could patients be disadvantaged if they have a visual identifier? In what way? *PROBE – stigma, violate rights to confidentiality, obscures individuality, leads to assumptions, seen as a burden by staff*
- their relatives? In what way
- for staff? In what way?
- for the ward/hospital?
-

6. Your vision?

Can you describe a vision for how visual identifiers should be used to work best for patients with dementia and staff? (PROMPT)

- *What would they look like?*
- *Where would they be placed?*
- *At what point would they be 'attached' to a patient? Should the decision be made in the community rather than in hospital?*
- *How can they be designed to make sure the people who need to know are aware of the patients' dementia, but protecting patients' privacy?*
- *Would you include people with suspected as well as confirmed dementia? Why and how would that work? What about when patients have fluctuating capacity?*
- *How would decisions be made about whether a patient had a visual identifier? Who should be involved? Should people give explicit consent? What if a patient lacks capacity?*

What else would need to be in place to make visual identifiers work in improving the care and experiences of patients with dementia in hospitals (e.g. principles, decision support, training, environmental changes)

Do you think there should be one standardised system nationwide to identify people with dementia in hospital? Why?

7. Closing and thanks

Finally, if your loved one was in a hospital that uses this identifier, what would you like staff to remember when they see it?

Check that the participant is still happy for you to use all the information provided and offer the possibility to erase sections of the recording. **Thank them for their time and contribution.**
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DA VINCI: INTERVIEW GUIDE FOR RELATIVES/CARERS AND PEOPLE WITH MEMORY PROBLEMS

Aim: to explore the views of people with dementia and their relatives/carers on the use of visual identification systems such as symbols, documents and training in providing care for people with memory problems

Consent: Check that everyone is happy to take part and that they know how long the interview will last. Talk through the information leaflet and consent form.

Ask the person with memory problems if they would like to take part and check that they understand the research is about and assess whether they have capacity to take part.

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1.   The researcher will read through the information sheet and will then explain the purpose of the study, reasons why the participant has been approached, and what taking part involves.

2.   The researcher will ask if the participant has any questions about the study or their involvement.

3.   The researcher will then ask the participant:

'To make sure you understand what taking part involves, could I check that you know:

a.   What the study is about? (answer: visual symbols and memory problems in hospital or having a memory problem in hospital or similar)

b.   Why you've been asked to take part (answer: to find out how I feel about being in hospital and/or having a memory problem in hospital)

c.   What we are we asking you to do (answer: to take part in an interview/have a chat)

If the person with dementia gives correct answers to all three questions, they will be deemed to have capacity. If not, ask relatives /carers if they consent to take part to be interviewed from their perspective.

Introduction

This research is about people with dementia experiences of being in hospital.

I want to start by checking that you are happy for me to use the term dementia. If not what would you prefer?

Could you tell me about a time when you [or your relative –as appropriate] went to hospital?

Probe for why admitted, how long they were in, how often they have been in hospital

Thinking about your most recent hospital stay [If relative – could you think about the most recent hospital stay when you were able to visit your relative], were you worried about problems you might have in hospital because of your dementia? What did you worry about?

What was your experience of being in hospital like? What was good and what was not so good? Ask for examples

- o Did you feel that you were treated kindly? What was it that made you feel this?
- o Did you feel staff talked to you about what was happening?
- o Did you ever get upset or distressed? What made you upset or distressed?
- o Did you feel safe [OR did you feel your relative was safe]? Why?

Did you feel that staff understood you and your needs when you were in hospital? What helped with this? (e.g. 'this is me'/patient profile)

Was there anything that you felt the hospital did to help to make your stay easier for you and other people with dementia?

Is there anything you would have liked to have been done differently?

Visual identifiers in hospital
We are interested in your views about using labels such as a flower or a butterfly or wristbands to identify you as having dementia.

Show examples of visual identifiers

Did you have a label to indicate you had dementia, such as a flower or a wristband in hospital? Can you describe what it was? If wristband - what colour? At what point did you get it during your hospital stay?

What were you told about why the hospital was using these labels?

How did you feel about having a label like this?

- What do you it is useful for? Does it help make your care better? How?
- Is it important for staff in hospital to know you have dementia? Why? When does it really matter that staff know you have dementia?
- Can you give an example from your own experience about when it helped that staff knew you had dementia?
- Is there anything bad about being labelled as someone with dementia in hospital? Can you give examples from your own experience?

Do you think it matters if other patients or relatives on the ward can see the label? Will they find out that you have dementia? Does this matter?

When the staff put the flower by your bed / gave you a wristband, were you asked whether you agreed to have it or not? Do you think it's important to ask people, before giving them a visible label like this? Why?

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Closing

How does it feel to be a person with dementia?

For relatives: How does it feel to have a family member with dementia?

If you had to go back into hospital what would you like staff to know about you? Why do you think this is important?

What else do you think is important in making sure that you, and other people with dementia, get good care in hospital?

Do you have anything else you would like to add?

Thank participant

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Supplemental material

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BMJ Qual Saf

DAVINCI interviews

Nodes\\Coding frame

Name
1. Challenges of providing care for PWD
bed crisis
behaviour eg aggressive-disruptive-uncoperative
Demand on staff time - stressful
difficulty establishing a baseline-history
discharge
environment
lack of motivation
nutrition
staff busy
staff turnover
staff understanding and compassion for PWD
why difficult to overcome
2. Description of VIDS
Type(s)
When is VID applied
Where VIDs placed
Who applied to
Who places VIDs
3. Purpose of VIDS

Supplemental material

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BMJ Qual Saf

Name
Organisational-co-ordination of care
Improve organisational status
Organisational
staff and ward level
VID for staff (signifier) - signals prompting for various responses
Compassion and empathy
consider additional needs
Manage and reduce risk
Modify communication style and approach
reassurance for relatives and patients
sense-making - dementia as a reason for distress and how to avoid-respond
4. Limitations, negative and unintended consequences of VIDS
doesn't tell you about the individual person
focus on the label not the person
may not want or recognise diagnosis
Meaning of label - stigmatising-negative attitudes-fear-judgmental
Obscures differences across spectrum of disease (severity)
overlooks specific individual needs
5. Practical challenges
delirium
getting a diagnosis of dementia in place
inconsistency
issue of multiple identifiers

Supplemental material

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BMJ Qual Saf

Name
lost at transfer between wards
mislabelling
patients missed from the system
6. Ethical challenges - tensions - points of contention
acting in the patient's best interests
confidentiality - privacy and disclosure
Need for consent
stigma
whether VIDs should encompass any memory issues or confusion without diagnosis
7. What's needed to make VID work
8. What's the role of other elements of local dementia strategies and how do they support VIDS or impact on effectiveness of VIDs
9. Ideal system
better at assessing difference between dementia and delirium
Consent from patients or relatives
everyone would know and understand
how it works
standardised
what information
where applied