

ARTICLE

# Through their eyes: informal carers' experiences of supporting a person with dementia on an NHS mental health inpatient ward

Hannah Partridge<sup>1,2</sup> , John Keady<sup>2,3</sup>  and Lydia Morris<sup>1</sup> 

<sup>1</sup>Division of Psychology, University of Manchester, Manchester, UK; <sup>2</sup>Greater Manchester Mental Health NHS Foundation Trust, Prestwich, UK and <sup>3</sup>Division of Nursing, Midwifery and Social Work, University of Manchester, Manchester, UK

**Corresponding author:** Hannah Partridge; Email: [Hannah.Partridge6@nhs.net](mailto:Hannah.Partridge6@nhs.net)

(Accepted 23 January 2025)

## Abstract

In the UK, when people with dementia are regarded as a risk to themselves or others, they are usually admitted compulsorily onto a National Health Service dementia inpatient ward, under the 1983 Mental Health Act. Remarkably little is known about the experiences of informal (family) carers supporting these individuals with dementia during their stay; this study is the first to explore those experiences.

Qualitative, semi-structured interviews with 12 informal carers with a family member admitted to an NHS dementia inpatient ward in the Northwest of England were analysed. The reflexive thematic analysis identified 4 main themes – (1) Initial adjustment and transition; (2) Becoming a visitor; (3) Receiving support and sharing expertise; (4) Planning for the future – and 15 sub-themes. Some carers experienced traumatic events in the build-up to admission and felt overwhelmed, worried, guilty and stressed during the stay, whilst others felt relieved that the person with dementia was no longer at home. The ward environment was regarded as safe and practical, albeit 'stark'. Staff care was seen as high-quality; carers appreciated support, when available, from a range of care staff and carer groups. Communication with ward staff was reported as 'mixed'; positives were receiving information leaflets, attending ward rounds and having informal conversations with staff. Carers often felt excluded from future care planning.

Preliminary suggestions for practice and policy recommendations include enhanced informal carer support during the admission, improved communication with ward staff, making the ward environment accessible and 'homely', and explaining staffing levels prior to admission.

**Keywords:** carer; dementia inpatient ward; Mental Health Act 1983; transitions; visitor

## Introduction

In the United Kingdom, National Health Service (NHS) mental health inpatient wards for people with dementia (subsequently referred to as dementia inpatient wards) offer

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intensive assessment, monitoring, care planning and, where necessary, pharmacological and non-pharmacological treatment (Dementia UK, 2023) for people with dementia who have become distressed to a point where they may pose a risk to themselves or others (Gray *et al.* 2021; Pinner *et al.* 2011). Carer stress or exhaustion may also contribute towards an admission (Wolverson *et al.* 2024). For the person with dementia, an admission to a dementia inpatient ward invariably occurs under a section of the Mental Health Act 1983 (Department of Health 1983) owing to issues around the person's informed consent, capacity and level of perceived and/or actual risk (Jones *et al.* 2022). At present, it is unknown how many individuals are admitted to such wards each year.

Remarkably little research has been completed on dementia inpatient wards. The lack of information on the operational functioning of dementia inpatient wards, along with the lack of research into them, is perhaps understandable given that the most recent national strategy documents and implementation plans, including the Prime Minister's Challenge on Dementia 2020 (Department of Health 2012, 2015, 2016), failed to mention the needs and future plans for dementia inpatient wards, concentrating instead on community and acute hospital settings.

However, where it exists, the literature exploring dementia inpatient wards reveals a range of diverse and arguably disconnected studies that cover: physical health monitoring procedures (Shanley *et al.* 2023), the meaning and concept of 'complexity' in dementia (Jones *et al.* 2022), use of life story work in improving care (Gridley *et al.* 2016), the ingroup identity and emotional labour of health-care assistants (Bailey *et al.* 2013; Lloyd *et al.* 2011), virtual reality feasibility studies (Rose *et al.* 2021), medication audits (Wilson *et al.* 2015), use of psychological consultation (Murphy *et al.* 2013), characteristics and outcomes of individuals admitted to dementia inpatient wards (Wolverson *et al.* 2024) and, most recently, a detailed case study of patient experience (Jones *et al.* 2024).

The study by Wolverson *et al.* (2024) reviewed 36 international papers, mostly retrospective audits, to examine the characteristics, care and outcomes of individuals admitted to dementia inpatient wards. They found that the primary reason for admission was to manage distress behaviours that posed a risk to the person with dementia or others. The average length of stay was 41.3 days (range from 1 to 795 days). Discharge destinations varied with 10.6 per cent to 50 per cent of individuals discharged home, 14.4 per cent to 67.2 per cent returning to or entering long-term care and 8 per cent to 19.8 per cent discharged to a general hospital. Repeat admissions were rare.

There is only one known study that has researched the experiences of informal carers supporting an individual with dementia on a dementia inpatient ward. This was conducted by Wolverson *et al.* (2023) where the research team interviewed seven informal carers about their retrospective views and experiences of the admission process. The study highlighted the distress experienced by informal carers and the person with dementia during the build-up to admission, the sectioning process, and ultimately the admission onto the ward. Informal carers felt excluded from care, found mental health legislation difficult to navigate and believed that the admission had a negative impact on their relationship with the person with dementia. Of this sample, four carers discussed admissions that took place during the Covid-19 pandemic and three

experienced visiting restrictions; the authors acknowledged that this may have had an impact on the carers' reported experiences.

If specialist services are to improve the care that people with dementia and their informal carers receive, and remain in line with NHS and UK policy aims and recommendations (Health and Social Care Committee 2021; National Health Service 2019; National Institute of Health and Clinical Excellence 2018), it is important to gain a more rounded account of the experiences and impact of dementia inpatient ward stays on informal carers. With only one known study (Wolverson et al. 2023) exploring this area, this is a strikingly understudied aspect of care practice, particularly given the prevalence, vulnerability and complexity of this population. To the best of our knowledge, this study is the first to explore contemporaneous accounts of informal carers' experiences of dementia inpatient wards.

Our study aims to address the following research question: What are informal carers' experiences of supporting a person with dementia currently admitted to a dementia inpatient ward?

## Methodology and methods

### *Study design*

A qualitative methodology, utilizing face-to-face semi-structured interviews, was adopted to answer the research question. The use of a qualitative methodology allowed for an in-depth exploration of the everyday complexities and nuances of carers' experiences, emotions and personal meanings. Semi-structured interviews were used to facilitate this perspective whilst allowing for flexibility in response and ensuring that key topics were addressed. In consideration of the sensitive topics discussed by informal carers, protocols were established to manage potential risks and distress, including allowing time at the end of the interview for a 10-minute debrief to check on participants' wellbeing. Before each interview was concluded, local support group information and helpline contact numbers were provided on a debrief sheet that was handed to the informal carer. Experts by experience were consulted in the design stages of the study in line with best practice Health Research Authority (HRA) frameworks (Health Research Authority 2021).

### *Participants and recruitment*

Informal carers were eligible if they were the main informal (unpaid) carer for someone with dementia who was currently undergoing a stay on an NHS dementia inpatient ward. The main informal carer was identified by asking potential participants: 'Who is the main person that visits and provides care for the person with dementia?' Informal carers with a range of relationships were eligible, such as spouses, adult children, siblings, friends and in-laws. Informal carers were excluded if they had insufficient English language skills to understand the questions and discuss their experiences in detail, were professional (paid) carers, were unable to give informed consent or were under the age of 18. The language of informal carer is used in the remainder of this article to operationally define the main person that visited the ward and provided care at home for the person with dementia prior to their admission.

Purposive sampling was utilized across five dementia inpatient wards in the Northwest of England. Three wards were single-sex wards for people with dementia, whilst two wards were single-sex 'older person' wards for individuals with a range of mental health conditions, including dementia. Recruitment was initiated by the first author contacting ward managers and/or the clinical psychologist(s) attached to the ward. Study information was provided to interested informal carers by the ward manager or clinical psychologist and a consent-to-contact form was completed. In a small number of cases where physical consent-to-contact forms could not be used, verbal consent was obtained and documented locally by ward staff on NHS Trust clinical records. Following telephone eligibility screening by the first author, a time slot was arranged for a face-to-face interview, to be completed alone with the main informal carer either at their home or in a confidential space on the ward. Interviews ranged from 60 to 90 minutes in duration and at the conclusion of each interview, as a thank-you for the time spent participating in the study, the informal carer was presented with a £10 Amazon voucher.

### **Data collection**

Informed consent was obtained for the informal carer, and demographic information was collected for both the informal carer and the person with dementia, to contextualize experiences and the overall sample. A topic guide, informed by previous literature (and included as a supplementary file to this article), was developed and reviewed by an expert by experience, that is, an individual with experience caring for a relative with dementia. Semi-structured interviews, supported by the topic guide, were conducted between May and December 2023 by the first author. Recruitment ended when informational power was deemed sufficient (Malterud *et al.* 2016). Informational power was reached by the first author and the research team (*i.e.* all authors on this article) regularly reviewing the interview transcripts and collaboratively assessing the need for additional data collection. Data saturation was reached when subsequent interviews yielded repetitive information, indicating that the generated themes and insights comprehensively addressed the research question.

### **Data analysis**

Interviews were audio-recorded and transcribed verbatim. Reflexive thematic analysis (RTA) (Braun and Clarke 2019) was employed to report the shared meaning and reality of participants' experiences, with the aim of identifying clear implications for practice (Braun and Clarke 2020). Data analysis consisted of six stages, as outlined in Table 1. Relevant ethical approvals to conduct the study were obtained from the NHS Research Ethics Committee and the HRA.

### **Findings**

Interviews were conducted with 12 informal carers who met our operational definition. Participant characteristics are summarized in Table 2. Although the length of time on the ward at the point of interview was not formally collected, this ranged from five weeks to six months.

**Table 1.** Details of the thematic analysis

Stages	Analysis of interview data
1) Familiarization with the data	The first author conducted all interviews and transcribed all the data. The transcripts and audio recordings were repeatedly read and listened to by the first author to facilitate data immersion.
2) Systematic coding of the transcripts	The first author systematically coded the dataset by identifying common key words, phrases and ideas expressed by participants. Data were managed using NVivo Version 12 (QSR International [now part of Lumivero] 2018).
3) Searching for themes	Themes and sub-themes were generated in relation to coded data extracts across the entire dataset by the first author. These themes were then reviewed by all members of the research team. The raw data were regularly referred to, and triangulation and reflective discussions with the wider research team supported the validity and the credibility of the themes. With RTA, researchers play an active role in the interpretive processes within data analysis (Gough and Madill 2012; Byrne 2021). Given this, the research team remained grounded in the data, whilst also recognizing and discussing how the themes might have been shaped by reflexive engagement.
4) Reviewing the themes	A detailed thematic map was created; coded extracts and quotes were identified to support the themes. The themes were examined by the research team to establish whether they were coherent and externally heterogeneous and had explanatory power.
5) Defining and naming the themes	Through further team discussions, a list of refined themes was created. Reflective team discussions and data-driven approaches supported the team (all members of the authorship) in defining and naming the themes and sub-themes to capture each theme's essence.
6) Producing the report	The qualitative results were finalized and the narrative was written up.

Four themes were identified from this approach to sample generation and data analysis, namely: (1) Initial adjustment and transition; (2) Becoming a visitor; (3) Receiving support and sharing expertise; and (4) Planning for the future. Each theme had a range of sub-themes and these will now be described and supported through the data. The theme numbering is not intended to be hierarchical.

### *Theme 1: Initial adjustment and transition*

This first theme describes the early experiences of informal carers and their initial adjustment and transition to the admission of the person with dementia to the dementia inpatient ward. It is a time of great uncertainty and change and the theme has been developed into four sub-themes, which will be reported sequentially: Build-up to admission; Impact on wellbeing; Initial visiting experience; and Communication at admission.

#### *Build-up to admission*

Informal carers discussed the stress of both the build-up to admission and the admission process itself. Informal carers recalled multiple interactions with emergency

**Table 2.** Demographic information on the participants (informal carers) and the person with dementia that they were supporting on the ward

	Participant characteristics ( <i>n</i> = 12)	Individual with dementia characteristics ( <i>n</i> = 12)
		<b>Data provided by the informal carer participant</b>
Age (years)	Age range = 34–84 years	Age range = 62–88 years
	Mean = 66 years (SD = 15)	Mean = 78 years (SD = 8)
Sex	9 females, 2 males, 1 non-binary	4 females, 8 males
Relationship to the person with dementia	8 wives, 2 daughters, 1 husband, 1 son	
Total number of years as a carer for the person with dementia	Range = 2–9 years Mean = 5 years (SD = 2)	
Type of dementia		Alzheimer's disease ( <i>n</i> = 2), Lewy body dementia ( <i>n</i> = 2), Alzheimer's disease and vascular dementia ( <i>n</i> = 2), vascular dementia ( <i>n</i> = 2), frontotemporal and primary progressive aphasia ( <i>n</i> = 1), atypical Alzheimer's disease ( <i>n</i> = 1), mixed vascular dementia ( <i>n</i> = 1), mixed Alzheimer's disease ( <i>n</i> = 1)
Number of previous admissions on to a dementia inpatient ward		11 participants had 0 previous admissions 1 participant had 1 previous admission

Note: SD = standard deviation.

services and often described these as ‘traumatic’ and ‘horrible’ experiences, observing use of restraint, miscommunication among ambulance, police and mental health services, and the person with dementia being placed in ill-equipped and inappropriate hospital settings. Yet, informal carers also reflected on the necessity of emergency services’ involvement owing to difficulties in managing the risk behaviours and their own stress levels, as this slice of data illustrates:

*I had been talking to the doctors about it, and they were saying, you know, if you're in danger, you have to phone 999 [emergency services telephone number in the UK]. That's an awful decision to make ... but in the end I thought ... you have to make the call. So I phoned 999. (Participant 1/wife)*

Two informal carers spoke positively about the emergency services and hospital staff, describing high levels of empathy, patience and understanding of dementia. Throughout the interviews, there was a sense of informal carers having a lack of choice or control around the admission and sectioning process.

Informal carers also discussed their preconceptions of the ward, such as imagining ‘people in white gowns’ and the ward-based, institutional setting of the 1975 film *One Flew Over the Cuckoo's Nest*:

*I had no experience of this before, no experience of psychiatric units, and I don't want to be disrespectful in any way, but you think of One Flew Over the Cuckoo's Nest. (Participant 10/wife)*

Two informal carers had previous experiences of visiting inpatient mental health wards and they described feeling less overwhelmed at the thought of the dementia inpatient ward because of this, as this personal testimony highlights:

*I've visited people on mental health wards before, secure ones, so it wasn't like a great big shock. (Participant 5/wife)*

Whilst not a main focus of this study, it is acknowledged that experiences in the build-up to admission are highly likely to have an impact on the wellbeing of informal carers and, potentially, their preconceived view of the ward.

### **Impact on wellbeing**

Several informal carers experienced high levels of stress in the weeks following admission, had difficulty concentrating and experienced poor sleep. Some described losing weight. In contrast, others felt relieved knowing that the individual was safe and receiving high-quality care. Furthermore, some informal carers described having more time for themselves and sleeping better:

*I actually managed to get more than two hours' sleep at night. (Participant 5/wife)*

The relinquishing of personal care tasks was a significant relief for some informal carers, particularly for sons and daughters:

*Things like attending to personal care ... that was a big element of the stress it was causing us as a family ... so I think when I see the nurses and the team do that here, that's the bit that we feel is particularly useful. (Participant 4/son)*

Informal carers spoke about the difficulty of balancing other life stressors whilst continuing their role as a carer, such as managing their own physical and/or mental health, work commitments, other caring responsibilities, home chores and finances:

*I think a lot of people might think that ... when someone goes into hospital you're not as busy anymore, but you still are ... There's still things at home to do, there's still things in your own life to do. (Participant 5/wife)*

Some spousal carers also reflected on the difficulty of adjusting to living alone:

*See, I've never lived on my own ... so it's a big learning curve. For my generation, there's a lot of women my age, generation, that have not lived on their own. (Participant 2/wife)*

Most informal carers in the sample reflected on how the high quality of care on the dementia inpatient ward had reduced their stress levels and provided a level of reassurance:

*Now she's here I am much more relaxed just because I know she's in, you know, she's getting the best possible medical care ... I do feel like she's being looked after by people that really know what they're doing. (Participant 3/daughter)*

Informal carers therefore experienced a mix of stress and relief after the person with dementia's admission to the ward. Although finding reassurance and reduced stress from high-quality care, many still faced personal challenges in managing their own wellbeing and daily responsibilities.

### **Initial visiting experience**

Often informal carers did not visit immediately after admission, with many being advised to allow time for the individual to settle in. Therefore, carers usually visited the next day or a few days later. Informal carers reflected on finding visiting upsetting and difficult, especially at the start of the admission process:

*At first we only stayed an hour at the most because it was really upsetting, and hard work. (Participant 2/wife)*

The distance for carers to travel to the ward varied from 5 to 50 minutes, with some using public transport to provide additional social contact and avoid the stress of parking. In some cases, other family members visited first and relayed information to the carers to help them know what to expect. The frequency of visiting varied from every day to once a week. Common phrases used to describe the initial visiting experience were: 'stressful', 'overwhelming', 'frightening' and 'lots of unknowns'. These experiences point to the need for a more organized system of information and better preparation of informal carers for their initial exposure to the ward and its physical environment/location/atmosphere.

### **Communication at admission**

Informal carers had mixed experiences of communication with staff during an admission. Some informal carers received leaflets providing information about sectioning under the Mental Health Act (Department of Health 1983), ward rounds, visiting and mealtimes; they also had a tour of the ward. Although many informal carers found these inductions helpful, it was somewhat overwhelming:

*I guess I didn't take too much in initially ... In the first few weeks, I was given a lot of information ... It is good because you have to have it, but it's also quite overwhelming. (Participant 10/wife)*

Other informal carers did not receive information leaflets and felt they had to ask staff questions and find things out for themselves:

*I didn't really get all that sort of basic information but, because I'm nosey, I'd already Googled it ... and the staff are always available if you need to ask them something. (Participant 5/wife)*

Generally, some informal carers appreciated the detailed information despite feeling overwhelmed, whilst others received little guidance and had to actively seek answers. Neither appeared a satisfactory solution.

### *Theme 2: Becoming a visitor*

This second theme explores the transition of informal carers to becoming 'visitors' to the dementia inpatient ward after, at times, many years of providing care at home for the person with dementia, often in very challenging circumstances. To capture this transitional experience, the theme follows five sub-themes, namely: Completing activities together; Adapting to the dementia diagnosis and progression; Emotional impact of visiting and 'being in limbo'; Adjusting to the ward environment; and Activities on the ward.

#### *Completing activities together*

Whether informal carers could complete activities with the person with dementia during visits was often dependent on the individual's mood, tiredness level and physical health on the day. Therefore, informal carers spoke about the importance of 'pitching the visit' appropriately:

*I can pitch it properly so I don't say anything upsetting. If he's been in a grumpy mood or if he's sleepy, I know not to make the visit too long ... There's no point trying to have a really long, deep conversation with him.* (Participant 5/wife)

Previous hobbies were completed together, such as sewing, walks in the garden, jigsaws, colouring and listening to music. Informal carers also discussed sitting in the bedrooms or communal areas of the ward and sharing updates from other family and friends or talking to staff. Specific tasks, considering the individual's ability level and previous interests, were also completed together:

*I brought bits of like patchwork fabric ... because she can't speak that well now so I can get them out and just crumple them up, and she'd fold them up and put them back in the box. That's a bit of an activity.* (Participant 3/daughter)

Informal carers also brought in items from home, such as newspapers or specific books of interest, for example books on *Doctor Who* or *Star Wars*, or car manuals. As the individual's dementia progressed, informal carers reflected on adapting activities:

*It's got pictures as well so he doesn't have to concentrate too hard; we can just look at a picture and talk about that ... But there's not a lot we can actually do together because of his attention span, and because of his cognition. So I just do what I know he's capable of.* (Participant 5/wife)

Some informal carers also supported the individual on trips out of the ward, such as walks around the building, to garden centres, the golf range, shopping or, in a few cases, returning home. However, some informal carers were worried that undertaking such activities might cause the person with dementia not to want to return to

the ward; unfortunately, in one case, this resulted in the need for emergency services' involvement:

*The more familiar he got with being home, he didn't want to come back ... He refused to come back, and I had to unfortunately get an ambulance. (Participant 10/wife)*

Whilst some informal carers also shared photographs with the person with dementia on the ward, others avoided this activity so as not to upset the individual and remind them of home or bereaved family members. Similarly, some informal carers avoided certain topics of conversation, particularly about home, their garden and personal items.

### ***Adapting to the dementia diagnosis and progression***

Informal carers reflected on the difficulty of adjusting to the dementia diagnosis and watching its progression. A common narrative emerged of 'missing the old version' of the person with dementia, as these two extracts from the data illustrate:

*And I sort of keep thinking about the normal [husband], but he's never going to be normal [husband], is he? (Participant 6/wife)*

*I miss the old [husband] ... I don't miss the current [husband]. (Participant 1/wife)*

Informal carers also grappled with the sense of helplessness and lack of treatment for dementia:

*I feel helpless that you can't really do anything ... you're watching this sort of terrible decline. There's nothing you can do to make it better. (Participant 3/daughter)*

Personality changes were also upsetting for informal carers to witness. One daughter discussed how difficult it was to see her mother, who was previously 'quiet as a mouse', saying 'hurtful' and 'upsetting' things during a visit:

*They [staff] all kept saying, 'It's the dementia talking', and I said, 'Yes, I know, but it still hurts.' ... It's just so hard watching that person disappear and morph into somebody else. (Participant 11/daughter)*

In some cases, informal carers spoke about how it may have been better if the individual had died, and how they were glad that the individual could not see how they are now:

*My greatest wish, and what he would want as well, is that he dies ... He's never accepted the fact that he has dementia. Never. (Participant 1/wife)*

*I'm glad that he's not as aware of it as he could be. Because it would be more upsetting. (Participant 5/wife)*

Informal carers expressed attempts to maintain the individual's dignity, and described not wanting others to see them, preferring for people to remember them as they were:

*I don't want them to see [husband] like that. And I don't think [husband] wants them to, really ... He's not capable of making that decision but ... I'm trying to keep his dignity.* (Participant 2/wife)

Informal carers therefore struggled to adapt to the dementia diagnosis, expressing grief over the loss of the person they once knew, feelings of helplessness and a desire to preserve the individual's dignity.

### **Emotional impact of visiting and 'being in limbo'**

Narratives about the emotional impact of visiting contained notable descriptions of 'stress', 'guilt', 'fear', 'anxiety', 'fatigue' and 'never knowing what to expect'. Many informal carers discussed the 'constant worry' they feel when they are not on the ward:

*Your mind is always thinking about him and worrying. There's not a minute that goes by where I'm not thinking about it.* (Participant 10/wife)

Some informal carers described positive emotional experiences of visiting, such as finding comfort in being close to their relative:

*People are saying, 'You should get a life for yourself', but he's always been my life, hasn't he? So I just feel ... all right when I'm here with him.* (Participant 12/wife)

Similarly, one wife explained how she enjoyed visiting every day, and that it was better than sitting at home:

*My daughters say, 'Mum you don't have to go in every day', but I like to go in every day. Because what'll I do here [at home]? Sit down here and start thinking. I might as well be in there.* (Participant 9/wife)

Informal carers described the difficulty of balancing the desire to continue with their own life with the sense of guilt and having the responsibility to visit:

*If I don't go, or if he thinks I'm late, he thinks I'm dead so he gets himself all worked up and quite distressed. So I put pressure on myself to say 'Well, I do need to go and see him.'* (Participant 10/wife)

Guilt was a feeling that was commonly shared. Informal carers reflected on the inner conflict of feeling guilty about their relative being on the ward whilst also recognizing that they could not manage at home:

*The fear of having him back is as bad as him being there ... I'm so mixed up by that. Guilt-ridden, I suppose.* (Participant 2/wife)

Furthermore, many informal carers felt guilty for continuing with their life, especially when doing 'nice' activities such as going to the theatre, attending family events or taking holidays:

*When you don't come, and you want to have a day out ... you feel so guilty, which is ridiculous. And maybe they don't even know, but you know. So the guilt is a massive thing.* (Participant 7/wife)

Informal carers recognized the temporary situation of the dementia inpatient ward and reflected on the challenge of finding 'normality' whilst 'being in limbo':

*I can't continue with my new normal while we are still in limbo.* (Participant 10/wife)

Additionally, not knowing the length of time that the individual would be on the ward, or where they would be going next, added to this uncertainty:

*And of course nobody can tell you ... how long will [wife] be in care, you know? ... How long is a piece of string? That's really hard.* (Participant 8/husband)

The lack of information also meant that informal carers were unsure what to tell family and friends about the situation:

*I don't know what I'm telling them. [Husband]'s not living here but is he going to come back? I don't know what I'm telling them. I don't know what's happening ... I can't tell them of the future or whatever.* (Participant 2/wife)

As seen, informal carers experienced intense emotional strain from visiting, grappling with constant worry, guilt and uncertainty about the future, whilst also struggling to find a sense of normalcy amidst the unfolding situation.

### **Adjusting to the ward environment**

Many informal carers were initially shocked at the ward environment, especially when transitioning from a home or care-home environment. Although informal carers appreciated that the ward environment had to be practical for safety reasons, many described it as 'stark'. However, some informal carers were surprised at how nice the ward environment was compared to their initial preconceptions:

*I was thrilled. It just wasn't what I pictured in my head of people in white gowns walking round ... I really was dreading it, so to find it like it is, how clean and fresh and bright, it was just lovely.* (Participant 11/daughter)

Informal carers were also pleasantly surprised that patients had their own room, comfortable furniture and a communal garden space. Safety was also an important factor, and knowing that the facility was locked and that the individual was safe was reassuring:

*He's safe. I know that I can go home happy that he is safe, and he's cared for and getting the best care possible.* (Participant 10/wife)

Informal carers spoke about their initial impressions of other patients on the ward. Some were initially unsure whether the ward was just for people with dementia or was a mixed ward with patients experiencing other mental health difficulties:

*I was quite scared and didn't really know who else was on the ward ... [Staff member] might have said this was a ward for dementia patients, but I didn't even pick that up. (Participant 3/daughter)*

On the other hand, carers found it difficult to observe distressed behaviour on the ward:

*The difficulty really initially ... again it sounds awful, but the other patients ... that was quite distressing, and some patients were throwing their plates, and screaming. (Participant 8/husband)*

Several informal carers spoke about initially feeling 'scared', 'frightened' and 'intimidated' by the other patients, describing some as 'absolutely zombified' or 'crying all the time' and being unsure how to communicate and interact. Adjustment was therefore a transitional process and required time, information and support from the ward staff and, if available, from other family members and/or support networks.

### **Activities on the ward**

Some informal carers felt that there was a lack of information about what activities took place on the ward and how patients spent their day, and experienced a lack of consultation about what activities might be suitable and of interest:

*Activity wise, I'm not so sure what they do with her ... She is spending a lot of time in her room ... and sometimes I do worry actually about is she just sitting there doing literally nothing? (Participant 4/son)*

Other informal carers were aware of ward activities and were encouraged to take part in them. Some person-tailored activities were also discussed:

*He sees housekeeping ... He'll take the trolley and he'll push it for them [laughs] ... When the maintenance man is out and about, he'll carry his bag and hand him his tools. (Participant 10/wife)*

Here, informal carers also spoke about relaxation groups, arts and crafts, holding parties for national holidays, gardening, music and dancing, and interactive computerized games.

### **Theme 3: Receiving support and sharing expertise**

This third theme explores how informal carers experienced their interaction with the dementia inpatient ward and communication with ward staff. The theme is presented under the following sub-theme headings: Staff quality of care; Communication with staff; Support for carers; and Involvement in care.

#### **Staff quality of care**

High staffing levels were highlighted as a key factor that supported the high quality of care:

*The staffing levels are very high, which reflects the level of distress of the patients, really, doesn't it? But you know, crikey, where in the NHS do you get that? It's amazing.* (Participant 1/wife)

Informal carers also commented on feeling reassured when learning about how most staff were long-term rather than agency staff, and the benefits of having doctors on site:

*When she has a fall, a doctor sees her within a couple of hours ... That's lovely, that's first-class care.* (Participant 11/daughter)

Furthermore, informal carers noted that care provision was consistently high-quality throughout the day, and how observation of staff interactions provided increased reassurance:

*I can come at any time and the care is never any different ... I can hear them down the corridor chatting to [husband] or trying to encourage him to take part in an activity, so it has been really good.* (Participant 10/wife)

The relationships between staff and informal carers were also commented on, with one husband describing how he felt like '*part of the team*' (Participant 8/husband) and how staff regularly offered cups of tea and asked about his wellbeing:

*The first thing they'll do when you come in is ask 'Are you having two teas?' ... and they were interested in my welfare.* (Participant 8/husband)

Throughout the interviews, staff care was consistently commented on as being '*very high-quality*', '*highly skilled*', '*friendly*', '*caring*' and '*extremely empathetic*'.

### **Communication with staff**

Informal carers often felt that they needed to use their own initiative to ask staff for information or updates ('*I have to go and find out*' [Participant 1/wife]) rather than receiving regular, proactive communication from staff. However, many informal carers also commented on the usefulness of informal conversations with staff during visits to gather information:

*When I come on to the ward, because it's a secure one, someone has to buzz you in and bring me down, so I generally ask them how he's been, how's he been sleeping, has he had a bath. So we have that little chat on the way.* (Participant 5/wife)

Some positive examples of proactive communication from staff were described, such as staff informing carers when hands-on restraint had been used or if the person with dementia had fallen:

*I just can't tell you how nice it is to get a phone call saying 'Your mum had a fall today; she's fine, the doctor came round and she's fine' before you've had a chance to worry or think about it.* (Participant 11/daughter)

Informal carers who had attended ward rounds mostly found these a helpful opportunity to provide their thoughts on the individual's care and to stay up to date with information:

*We've had one meeting with Dr [name], and [the] deputy manager, and family, to discuss [husband] and so everybody had a chance to say what they want to say.*  
(Participant 2/wife)

However, other informal carers had not been invited or had been inconsistently invited to ward rounds. Furthermore, ward rounds were sometimes overwhelming for informal carers owing to the number of professionals attending them:

*It's a bit overwhelming because on the first one I think there was five or six people sat there, and just me.* (Participant 7/wife)

Despite the challenges of obtaining regular communication with staff, informal carers explained that when they asked staff questions, staff were responsive and active in finding out the information by reading notes, checking medication cards or asking other staff:

*If I have any concerns or questions, I know who to go and ask and I always get the answers, but I just don't have those regular meetings.* (Participant 10/wife)

Some informal carers commented on a lack of shared communication between staff, and information not being passed on, particularly when informal carers requested personal care for the individual, such as a haircut, shave or their toenails cutting:

*They'll say, 'Right, we'll pass that on', and then the lady will come in to cut the toenails and she'll say, 'No, he's not on the list.'* (Participant 7/wife)

Similarly, some informal carers had received mixed messages or incorrect information on matters such as medication changes, whether the individual had been showered that day, who the named nurse was, changes to care plans, and incorrect information about discharge.

Most informal carers felt involved in important decisions such as medication, which was often achieved through attending ward rounds. However, other informal carers felt that they were sometimes informed of changes after they had happened rather than being involved in collaborative decision-making: *'They ring me up and tell me what they're going to do'* (Participant 2/wife).

### **Support for carers**

Informal carers spoke about the support they received from the ward. Some informal carers discussed positive experiences of one-to-one therapy with the psychologist to support their adjustment and coping, and some carers described limited interactions with other informal carers on the ward (*'exchanging pleasantries'* and *'small talk'*). Where carer support groups did not exist on the ward, informal carers expressed a desire for one:

*I think it would be lovely to have the families meet in a room and just discuss things ... because you could all reassure each other.* (Participant 11/daughter)

If a carer group was already established on the ward, some informal carers were aware of it, although none of the carers interviewed had attended one. In these cases, informal carers spoke about preferring to rely on the support of close family rather than attend a group. Informal carers also spoke about their desire to learn more about dementia and its progression, with some informal carers attending courses or searching online to obtain this information:

*So when he got dementia, I decided to go on all these courses and learn as much as I could. And I went online and got lots of information and set up a big file with ... so I've tried my best to just learn as much as I can.* (Participant 7/wife)

Informal carers also requested to receive more information on other relevant topics such as power of attorney policies and deprivation of liberty safeguards.

### **Involvement in care**

Personal care tasks for the person with dementia were mostly managed by the ward staff; however, one husband spoke about continuing to shower his wife owing to her level of distress at staff performing this caring act. Some informal carers also supported their relative to get dressed or choose clothing in the mornings, especially if staff found it difficult to encourage them to change clothes. Informal carers also relayed personal hygiene requests based on the individual's preferences:

*At the moment he has sideburns [laughs]; he's never had sideburns. So I spoke to three or four members of staff and said, 'Do you think you could ask them to get them off?'* (Participant 7/wife)

At times, informal carers were encouraged by staff to stay for mealtimes to help encourage their relative to eat and to allow them to spend quality time together:

*What they always try to do is encourage the families to stay at mealtimes, so you can have a meal together as a couple or family.* (Participant 10/wife)

However, in other cases, informal carers spoke about mealtimes being busy and the ward preferring visitors not to attend during these periods.

Informal carers' experiences of sharing their own expertise and knowledge were mixed. For example, at admission, some informal carers were invited to provide information about their relative's background, hobbies, likes, dislikes and dementia presentation. This request was often completed using a form, but in some cases it took place via a telephone call with a staff member prior to admission. In contrast, other informal carers were not provided with a clear opportunity to share their knowledge and expertise.

When sharing of expertise took place prior to, or at the time of, admission to the ward, this was positively reviewed by informal carers:

*I spoke to a senior nurse, and he went through a full pack with me about [husband], his likes, his dislikes, a bit about his background ... how long has he had his diagnosis, what's his character, what's his behaviour like ...? It showed me they are caring and needed to know these things to help him. (Participant 10/wife)*

One wife explained how this information was used to create a visual display in her husband's room:

*This man rang me and he said, 'Could you tell me all about [husband]?' ... and they printed it out with a little thing of [football team name] and it's up in his room. So I thought that was really good. (Participant 6/wife)*

Some informal carers placed photographs around the individual's room to display relevant background information, hobbies and interests, and family members that they may mention (*'I've put a big picture of me near his pillow'* [Participant 12/wife]).

Informal carers also discussed how they continued to provide information to staff on behalf of their relative, such as their clothing preferences, food dislikes, personal values and preferences for ward activities:

*Sometimes he's not dressed as well as he should be ... [Husband] was always quite smart. (Participant 2/wife)*

Informal carers also spoke about using their expertise to support staff to de-escalate situations:

*I only live five minutes down the road, so I've said, 'If you ever need a de-escalation, give me a call, I'll come up', so we've done that [a] couple of times. (Participant 5/wife)*

Throughout this theme, informal carers often commented on how busy staff were, and some spoke about *'feeling like a burden'* when asking staff to do something for them, and *'not wanting to be a nuisance'* by asking questions. Interestingly, when discussing negative aspects of communication with staff, informal carers were often quick to follow this up with an acknowledgement of how busy staff were and a recognition that communication was not always a priority when staff were focused on providing care for the patients on the ward.

#### **Theme 4: Planning for the future**

This fourth and final theme describes informal carers' views and experiences of being involved in discharge planning and the planning for the future that happens at certain points and times in the admission procedure. The theme is structured around the following three sub-themes: Communication and involvement in care planning; Managing uncertainty; and Hopes for the future.

### **Communication and involvement in care planning**

Several informal carers spoke about the lack of communication regarding future care planning, particularly with regard to social workers ‘*calling out of the blue*’ and not keeping them informed of plans or decisions:

*[Social worker] rang me up and said, ‘We are assessing [husband]; he’ll be moved.’ I’d never heard about it ... she never came to see me. And just to tell me this over the phone, it was just horrible. (Participant 9/wife)*

Furthermore, compared to the dementia inpatient ward, informal carers were concerned that care homes had a reduced quality of dementia-specific care and lower staffing levels:

*If we hadn’t been to the care home first, this would have set our expectations up for looking for somewhere. We’d never find it, of course, in a care home because it’s a different ... situation ... different staff ... It’s just when they do leave here, the next stage will just not feel right. (Participant 11/daughter)*

Additional financial pressures were expressed by those supporting individuals on a Section 2 (compulsory admission for up to 28 days) of the Mental Health Act (Department of Health 1983), where aftercare is not funded by the state. Conversely, those supporting individuals on a Section 3 (compulsory detention for up to six months; can be renewed if appropriate) of the Mental Health Act (Department of Health 1983), where aftercare is funded, reflected on the alleviated financial stress:

*She has gone onto a Section 3 ... which means [wife’s] care is funded. That’s a relief to me ... that’s taken a lot of stress off me. (Participant 8/husband)*

Informal carers also found it difficult to find an appropriate care home, discussing how many were not local or could not meet the level of need for the individual.

### **Managing uncertainty**

Informal carers spoke about the uncertainty of the future in terms of where the individual would be moved to when discharged. At the time of interviews, most informal carers had been informed that their relative was not likely to return home and that a dementia-specific care home would be the most appropriate future care setting. Given this, informal carers reflected on a sense of responsibility to find a care home that was of high quality and in the local area to allow them to visit regularly:

*That will be his home for the rest of his life. And I’m going to have to visit him, be it every day, every other day ... so I don’t want him to be going somewhere substandard and out of [the] area. (Participant 10/wife)*

Some informal carers felt conflicted about this and questioned whether they would be able to support their relative at home again, whilst others recognized that this would not be possible, ‘*It’s not what I want ... but it’s what’s best*’ (Participant 8/husband). This inner conflict was a common thread across the dataset.

## Hopes for the future

A number of informal carers expressed hopes for a future care home, such as being able to make their relative's room more homely and the benefits of increased consistency and certainty of the stay, compared to 'being in limbo' on the ward:

*Then I think I can take a step back and breathe a bit and think right ... now I can try and get a new normal again. But until that, I won't get that peace because he's still here, he's in limbo. (Participant 10/wife)*

Informal carers anticipated that a care home's stability and homelike setting, with a personalized room of familiar belongings, would provide comfort and uphold their family member's dignity and sense of identity. This future transition represented a relief from the uncertainty of the ward, offering a structured, reliable environment. Some informal carers also anticipated that this stability would ease some of their own anxieties, allowing them to focus on rebuilding their personal lives and establishing a 'new normal'.

## Discussion

To the best of our knowledge, this study is the first to contemporaneously explore informal carers' views and experiences of dementia inpatient wards. Semi-structured interviews with 12 informal carers [*i.e.* the main carer at home and visitor to the ward] revealed 4 distinct, yet interconnected themes. Findings revealed that admission was a stressful and uncertain time for informal carers, with multiple traumatic events often occurring in the build-up. Informal carers had common preconceptions about dementia inpatient wards based on past experiences of hospital wards, mental health inpatient wards and/or media influence, including films. On the one hand, the security, quality of care and dementia-friendly environment of the dementia inpatient ward provided reassurance and relief to many informal carers. On the other hand, the ward was often described as 'stark' and informal carers found it difficult to witness distressed behaviours of other patients. Visiting a person with dementia was an overwhelming, stressful and tiring experience for most informal carers, whilst others appreciated the social contact and routine. The quality of care provided by ward staff was mostly regarded as positive, caring and high-quality, and the high staffing levels, long-term staff and dementia-specific care approaches increased informal carers' sense of reassurance about the environment of care. That said, the informal carers' experiences of communication with ward staff were mixed, particularly at the point of admission.

Despite a lack of research within dementia inpatient wards, the study findings can be considered in relation to literature exploring carers' experiences of supporting someone with dementia in community and care-home settings. For instance, a striking journey of adjustment and role transitions were seen throughout the informal carer interviews – adjusting to living alone, adapting to the dementia diagnosis and progression, and transitioning from a role identity of 'carer' to that of 'visitor'. Interestingly, the roles and responsibilities that informal carers discussed in this study revealed some similarities to those completed by visiting carers to care homes for people with

dementia, such as advocating for the person with dementia (Graneheim *et al.* 2014; Johansson *et al.* 2014), monitoring care and wellbeing (Hayward, Gould, Palluotto, Kitson and Spector 2021), completing activities together (Lee *et al.* 2022) and establishing relationships with staff (Hayward, Gould, Palluotto, Kitson, Fisher and Spector 2021).

Uncertainty and role ambiguity were also common themes within this study. For example, informal carers were unsure what items they could bring into the ward, whether they could stay for mealtimes and how best to obtain relevant information from staff. The difficulties stemming from unclear roles and adjusting to new caregiving responsibilities have been shown to negatively impact carer wellbeing within the care-homes literature for people with dementia (Cottrell *et al.* 2018; Gaugler *et al.* 2004). Concerningly, role transitions, uncertainty and ambiguity are arguably even more complex within dementia inpatient wards given the impermanence of the situation and the possibility of the person with dementia returning home. A further consideration is that an admission to a dementia inpatient ward occurs via involuntary sectioning under the Mental Health Act (Department of Health 1983), rather than being an active carer choice – as it is with most placements into care homes. Therefore, this lack of choice and control may also influence carer wellbeing (Pertl *et al.* 2019). Indeed, the nuances of informal carer experiences within dementia inpatient wards, although sharing some similarities with experiences in care homes for people with dementia, require further exploration with regard to the unique challenges and experiences faced, and the impact of these on subjective wellbeing.

Like Wolverson *et al.* (2023), our work suggests that informal carers experience feelings of grief and guilt, not only in relation to the person with dementia being admitted to the ward but also in regard to continuing with their own lives. It was difficult for informal carers to somehow ‘stand back’ and witness the ‘decline’ of the person with dementia, and to balance their own life with their continued carer role, albeit one that was going through a new transition. These experiences can be seen as being similar to carers’ experiences of supporting someone with dementia in a community or care-home setting (Lindeza *et al.* 2020). However, as shared in this article, dementia inpatient wards also present some unique challenges to informal carer wellbeing. For example, informal carers do not know how long the person will stay on the ward, they are unsure where the individual will be discharged to and the involuntary nature of the admission can lead to an ‘inner conflict’ for some carers. Again, this demonstrates the importance of future research exploring the specific challenges that dementia inpatient wards present, and their impact on informal carer wellbeing.

Our study also found that the provision of psychological support to informal carers was varied; interestingly, even when carer groups were available on the dementia inpatient ward, none of the carers interviewed had attended them. Unfortunately, a lack of psychological support for carers was also found by Wolverson *et al.* (2023) in dementia inpatient wards, and other studies have also found this within community and dementia care-home settings (Bressan *et al.* 2020; Brooks *et al.* 2021). These findings not only highlight a need for psychological provision to be offered more consistently and more thoroughly across dementia inpatient wards but also demonstrate the need for personalized and targeted carer support, given that carer groups were not utilized, or perhaps not accessible, for all carers. Future research may wish to explore

the specific psychological needs of informal carers on dementia inpatient wards, and the most suitable and appropriate methods of delivery.

The negative effects on informal carer wellbeing may be further exacerbated by the lack of information and education that carers felt they had received around dementia, the mental health system, legislation and the sectioning processes. Wolverson et al.'s (2023) study highlighted a similar point regarding the lack of information carers receive about mental health law and services. Research in community settings and care homes for people with dementia has also highlighted a lack of meaningful education, training and role preparation, leaving carers in a state of confusion and distress throughout the dementia 'journey' (Bressan et al. 2020; Brooks et al. 2021).

Unfortunately, this lack of education, information provision and psychological support for informal carers continues to occur despite research demonstrating the effectiveness of psychological support, such as counselling, acceptance and commitment therapy, cognitive behavioural therapy and provision of training and education programmes, in improving carer wellbeing in the community and care homes (Cheng et al. 2020; Whitlatch and Orsulic-Jeras 2018). Interestingly, studies have also found that increasing informal carer involvement in care and improving communication and collaboration with staff can improve carer satisfaction within care homes for people with dementia (Hoek et al., 2021). This concept aligns with findings from the current study, as informal carers often spoke about the benefits of having a positive relationship with staff, effective communication and opportunities for involvement, in terms of improving their overall satisfaction and wellbeing.

Our study, along with wider literature across community settings and care homes, highlights the fact that informal carers continue to remain 'in limbo' with regard to psychological support, training and information provision. Future research may be advised to consider existing interventions and programmes that have shown success in community and care-home settings and to evaluate their use in dementia inpatient wards, whilst also considering the nuances of the dementia inpatient ward settings and experiences.

### Practice and policy recommendations

Our study findings have highlighted some important practice and policy recommendations. However, these recommendations are based on evidence from a limited sample and should be considered as preliminary suggestions that require further research to both authenticate and validate their effectiveness.

#### *Enhance informal carer support and involvement in care*

To enhance informal carer support and involvement in care, it is essential to provide consistent and accessible one-to-one psychological support services. Establishing regular carer support groups could foster community and shared experiences, even if participation is scarce, as it is possible that the offer of a group alone is enough to increase carers' sense of support. Informal carers should be provided with comprehensive information about dementia and its prognosis early in the admission process to better prepare them for future challenges. To facilitate informal carer involvement,

health-care providers should encourage participation in mealtimes and ward activities. Additionally, a structured system for collecting important information about individual preferences should be implemented, ideally through a pre-admission telephone call. This information could be utilized to create personalized visual displays in patients' rooms, promoting comfort and meaningful interactions.

### ***Develop effective communication with ward staff***

Protocols should be established to ensure that informal carers are regularly invited to ward rounds and receive relevant meeting minutes. Designating a named contact on the dementia inpatient ward for direct updates can enhance communication efficiency. Providing detailed information leaflets at admission, including about legal processes, ward demographics and helpful/prohibited items, is recommended. Informal carers may also benefit from a follow-up face-to-face meeting with ward staff a few weeks post-admission to reinforce critical information and address any questions. Additionally, staff wearing name badges can improve rapport and foster a more welcoming environment.

### ***Making the ward environment accessible and 'homely'***

Informal carers requested more information about what items they could – and could not – bring into the ward to make the environment more 'homely'. Understanding the composition of the ward, including whether all patients have dementia or if others have different mental health conditions, could help informal carers to better prepare for exposure to the ward environment. Moreover, individualized activities should be prioritized, taking into account each patient's background, interests and abilities, to promote engagement and a sense of belonging.

### ***Explaining staffing levels***

High staffing levels emerged as a significant aspect of high-quality care and a personalized care environment. This is particularly important in settings where patients have dementia and complex needs, as seen on the dementia inpatient wards sampled in this study. It is therefore crucial to advocate for similar staffing standards in care homes and other care settings where there is a high proportion of residents with dementia and complex needs.

### ***Rigour and reflexivity statement***

In RTA, the researcher's perspectives, experiences and biases are seen as tools for data analysis, not hurdles to overcome. It is argued that by embracing reflexivity during the data analysis process, researchers can navigate the inherently interpretive aspects of qualitative analysis with greater awareness and rigour, to deliver deeper understandings of the study phenomena (Gough and Madill 2012). All authors in this study reflected on the fact that they were all white British with professional experience and training in psychology or mental health nursing applied to research, academia and/or clinical

roles. Notably, all authors had personal experiences of a family member with dementia. The first author was a trainee clinical psychologist, and this study was undertaken as part of a clinical psychology doctorate programme. The first author reflected on their 'SOCIAL GRACES' (Burnham 2018) to understand how their various identities – researcher, clinician, student and colleague – could shape their interactions with participants and the analysis of the data. This self-awareness helped the first author recognize potential biases and power dynamics, ultimately enhancing the authenticity and depth of the insights gathered from the carers' experiences. By engaging with the concept of SOCIAL GRACES, the first author also acknowledged the importance of empathy, respect and relational dynamics in building trust with participants, which is essential for obtaining rich, meaningful data in qualitative research. All authors and participants were not known to each other prior to the study. The authorship/research team used systematic methods to analyse interview transcripts collaboratively, reviewed and agreed the coding methods and thematic structure together and engaged in reflective discussions; the first author kept a reflective diary throughout the conduct of the research process.

### Strengths and limitations

Most informal carers who took part were females (75%). Whilst this is reflective of the estimated gender balance of dementia carers (Alzheimer's Society 2020), it does limit the study's findings in terms of exploring the experiences of male informal carers on dementia inpatient wards. Although this study did not formally capture the participants' ethnicity, the cultural heterogeneity across the participants was limited. This was reflective of the overall carer population within the dementia inpatient wards and highlights a known need to improve access to specialist dementia care, as well as explore the experiences of more ethnically and culturally diverse populations within dementia services in the UK (Francis and Hanna 2020; Johl et al. 2014). The types of dementia of the corresponding individuals on the ward were varied, which provided a broad sample; however, Alzheimer's disease (17%) was under-represented compared to the general population (estimated 60% to 70% of dementia diagnoses; World Health Organization 2023). Additionally, the sample included individuals with rarer forms of dementia, such as frontotemporal dementia and primary progressive aphasia. It is important to acknowledge the potential differences in the experiences and needs of carers for these individuals compared to those with more common forms of dementia. Furthermore, owing to health-care systems differing across countries, the study findings can be considered only from within a UK context. Further research is needed with a larger, more diverse sample across dementia inpatient wards in the UK and worldwide.

Given discourses of power imbalance that are often present between informal carers and health-care professionals (Miah et al. 2020), the researcher–participant relationship may have presented a barrier to carers talking openly about their experiences, despite the first author's attempts to reiterate the importance of confidentiality and the lack of connection to the wards. Recognizing this, it is essential to reflect on the first author's own biases and position throughout the research process. It was important for the whole authorship/research team to remain aware of their own biases and positioning when interpreting the data and ensuring that the findings accurately represented

the informal carers' shared and subjective experiences. Interestingly, Miah *et al.* (2020) also highlighted how informal carers often report that involvement in research provides a sense of 'purpose and satisfaction', something that the first author also found during carer feedback.

## Conclusion

This study has provided an in-depth, novel exploration of informal carer experiences of dementia inpatient wards and has offered some preliminary practice and policy suggestions that can be explored further. This study has built on the known importance of understanding carers' experiences of people with dementia and has laid a foundation upon which further research into their views and experiences of dementia inpatient wards can be developed. More research is needed to explore this growing and complex field, and operationalized applications of additional findings should be applied within services.

**Supplementary material.** The supplementary material for this article can be found at <https://doi.org/10.1017/S0144686X25000078>.

**Acknowledgements.** We would like to express gratitude to all the carers who took part in our study. We would also like to thank the staff in the dementia inpatient wards across the Northwest of England who made this study possible.

**Financial support.** No external funding was received.

**Competing interests.** The authors declare none.

**Ethical standards.** All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional research committee. Full ethical approval was granted by the North of Scotland Research Ethics Committee and approved by the HRA and Health and Care Research Wales [REC reference 23/NS/0008]. Informed consent was obtained from all individual participants included in the study. While the data that support the findings of this study are not publicly available owing to privacy or ethical restrictions, they are available on request from the corresponding author.

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**Cite this article:** Partridge H, Keady J and Morris I (2025) Through their eyes: informal carers' experiences of supporting a person with dementia on an NHS mental health inpatient ward. *Ageing & Society*, 1–27. <https://doi.org/10.1017/S0144686X25000078>