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# 'Making the most of time during personal care': nursing home staff experiences of meaningful engagement with residents with advanced dementia

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#### **ABSTRACT**

**Objectives:** Dementia progressively affects cognitive functioning, including the ability to communicate. Those who struggle to communicate are often considered unable to relate to other people. Frontline care workers are in a position to connect with residents. However, we know little about their perspectives. The aim of this study was to understand how and when nursing home staff meaningfully engaged with residents with advanced dementia.

**Methods:** Semi-structured interviews, supplemented by informal conversations, were conducted with 21 staff from seven nursing homes. Inductive thematic analysis identified themes in the accounts. **Results:** Four themes related to *how* staff engaged with residents with advanced dementia (initiating meaningful engagement, recognising subtle reactions, practising caring behaviours, patience and perseverance). Two themes related to *when* meaningful engagement occurred (lacking time to connect, making the most of time during personal care).

**Conclusion:** A key barrier to implementing formal interventions to improve care is lack of staff time. Staff overcome this by using personal care time for meaningful engagement with residents. Their approach, developed through experience, is consonant with person-centred dementia care. Building on this, future research should use participatory approaches building on practice wisdom to further develop and evaluate meaningful engagement with residents with advanced dementia.

#### **ARTICLE HISTORY**

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#### **KEYWORDS**

Advanced dementia; care workers; experiences; meaningful engagement; nursing home; staff; time

# Introduction

Dementia progressively affects cognitive abilities, including the way a person communicates. This study focuses on people living with advanced dementia. The term 'advanced dementia' is used interchangeably in the literature with 'severe dementia' and 'end stage dementia' and refers to the point at which a person is living with profound functional, cognitive and physical impairments (Burns et al., 2006; Livingston et al., 2017) including incontinence, recurrent respiratory and chest infections and swallowing difficulties, often leading to pneumonia (Mitchell et al., 2004). When dementia is advanced, the ability to start conversations, process information and respond to questions also becomes increasingly impaired (Hanson et al., 2016). Often those who are unable to communicate verbally and have limited mobility are socially excluded as staff view them as unable to meaningfully engage in interactions (Watson, 2015, 2019).

The philosophy of person-centred dementia care challenges the assumption that people with advanced dementia can no longer meaningfully engage (Dewing, 2019; Kitwood, 1997). Kitwood (1997) proposed that, while dementia is a condition that affects the brain, the person's social environment, personal biography, health, and personality play a role in determining the way dementia affects each individual. The approach focuses on the importance of those with dementia receiving person-centred support from others who understand their unique response, to improve their day-to-day quality of life. Personcentred interactions raise the possibility of improving the

well-being of those living with dementia, despite the level of neurological impairment.

Person-centred dementia care is often conflated with the broader philosophy of person-centred care (Manthorpe & Samsi, 2016; Mccance et al., 2011). Given the broad and interchangeable use of person-centred care and person-centred dementia care, there is critical debate regarding the conceptual development and operationalisation of the concepts (Mccance et al., 2011). Mccormack et al. (2012) suggest several models have emerged, with some based on superficial decisions about choices related to activities of daily living (Mccormack et al., 2012). Person-centred care (as opposed to person-centred dementia care) is a term used to describe a standard of care that places the person at the heart of care delivery (Mccance et al., 2011). Its general focus is to help people to plan and express their choices about the health or care services they would like to receive. This appears connected with the notion of consumerism, rather than interdependence and negotiated choice in relation with others. It can be argued this type of model is not concerned with connections and relationships (Mccormack et al., 2012). In contrast, person-centred dementia care highlights the importance of connections and relationship for well-being and the significant role care staff play in ensuring such connections. Person-centred dementia care, for example, addresses why dementia manifests differently in different people, thus enabling those who support people to understand their behaviour and state of mind (Terkelsen et al., 2020). As a result person-centred dementia care is almost universally advocated in policy, research, and practice (Brooker, 2019).

Despite being universally embraced, a significant body of international observational research demonstrates that residents with advanced dementia are not commonly in receipt of person-centred dementia care and tend to spend their days alone with little interaction with anyone (den Ouden et al., 2015; Fauth et al., 2020; Morgan-Brown et al., 2011; Palese et al., 2016; Ward et al., 2008).

People with advanced dementia often live in nursing homes and depend on paid caregivers for support for all aspects of their daily life (Eisenmann et al., 2020). In the UK there are approximately 4400 nursing homes providing care for highly vulnerable people. In these settings, meaningful connections between staff and residents with advanced dementia rely on staff's motivation and capabilities (CARE QUALITY COMMISSION, 2017). Little research, however, has directly addressed care staff experiences of how and when they meaningfully engage with residents or explored care staff views on why in their experience residents with advanced dementia spend their days alone.

Research to date has largely focused on the effectiveness of interventions such as aromatherapy, music therapy, and animal assisted robots to promote meaningful engagement (O'connor et al., 2013; Rapaport et al., 2017; Takayanagi et al., 2014; van der Vleuten et al., 2012). Two recent studies report data gathered directly from care workers, giving rich reports of their engagement with residents with advanced dementia during everyday interactions (Kemp et al., 2021; Watson, 2019). The authors suggest inclusivity, personalisation and paying attention to embodied and inter-embodied selfhood, are important to ensure people with advanced dementia can be active in their relationships. It is unclear, however, how and when this is achieved in the context of everyday practice (Kemp et al., 2021; Watson, 2019).

However, in a publication from the same dataset as is used in the current article (Haunch et al., 2022) we described *what* facilitated staff to connect with residents with advanced dementia. We found that effective leadership was key to supporting care staff to enact connecting, understanding, accepting, and empathising with residents as part of their role. In the current article, we report on nursing home staff's perspectives on *how* and *when* they meaningfully engaged with residents in the context of everyday practice, drawing on their practical wisdom' (Cathcart & Greenspan, 2013) to advance understanding.

#### **Methods**

We adopted an interpretivist approach, considering reality to be socially constructed (Guba & Lincoln, 1994). Consistent with this, we employed a qualitative method based on semi-structured interviews, supplemented by informal conversations. This study is reported in accordance with the consolidated criteria for reporting qualitative research (COREQ) guidelines (Tong et al., 2007).

#### **Ethics**

The study protocol was reviewed, and ethical approval granted by the Humanities, Social, and Health Science Research Ethics Panel at the University of Bradford. Written informed consent was obtained from staff individually in 2018.

### **Data collection**

#### Setting

The study population comprised staff working in nursing homes that provided care for people living with advanced dementia.

#### Sampling and recruitment strategy

The nursing homes were part of the NIHR ENRICH initiative (NIHR, 2022) which maintains a register of 'research ready' care homes. Purposive sampling of nursing homes was used to gain a diverse sample from nursing homes that varied by size, location (rural vs urban) and quality rating. To learn from good practice, at least one nursing home was judged by the Care Quality Commission (CQC, the independent regulator for quality in England: (CARE QUALITY COMMISSION, 2016) as providing outstanding care. The lead author had previously had a role of bringing together researchers with 'research ready care homes' in the ENRICH initiative so in keeping with the aim to explore good practice, she was able to approach nursing homes where she had observed connections between staff and residents with advanced dementia.

Nursing home managers were approached through a phone call where the reasons for approaching them and what was entailed if they took part were explained. After this initial phone call further written information was sent by email, followed by a further phone call the following week where questions were answered. A date was then arranged to visit the nursing home. Once the nursing home agreed to participate, written informed consent from the provider or their nominee was obtained.

All members of staff, who cared for, or observed care of people living with advanced dementia, in those homes that had agreed to participate, were approached to take part and given a participant information sheet. Staff were invited to express an interest by contacting the researchers who were available to answer any questions, clarify queries, and take oral consent. Written informed consent was taken on the day of the interview.

#### **Procedures**

Semi-structured interviews were conducted in a private room within the nursing home between the hours of 9am and 5pm (Ritchie et al., 2014). The interview guide (Supplementary file 1) contained general questions about how and when care workers meaningfully engaged with residents with advanced dementia, along with what facilitated and prevented such engagement. This was followed by focused questions about who, what, why, where, when, and how meaningful engagement occurred. To gain detailed examples of meaningful engagement, we asked care workers to give specific examples of when they had connected. All interviews were audio recorded and subsequently transcribed with personal data being pseudonymised. Field notes were made, with informed consent, of the informal contact the researcher (KH) had with staff before and after interviews and during time spent in the nursing home. Field notes served as a means of documenting contextual information (Phillippi & Lauderdale, 2018), for example, about the overall setting. This enabled us to gain an understanding of staffing structures, demographics, relationships, organisation of care and visitors. Field notes were also used to note aspects of the care environment, such as sights, smells, sounds, and gain impressions of staff experiences shortly after they occurred. Field notes were kept as a separate document but linked with interview transcripts via participant number.

Data were collected in stages with analysis occurring concurrently (Nowell et al., 2017). The lead author (KH) primarily collected data, with the co-authors (MD, JO) scrutinising interview transcripts to ensure the data collection was appropriate. All authors were involved in the analysis of data [as described above]. KH, a PhD student at the time, is experienced in

qualitative and realist methods. JO and MD are experienced Professors in applied dementia care. Data saturation occurred when the authors agreed no new themes were arising.

#### **Data analysis**

We used inductive thematic analysis to analyse the data (interviews and field notes) following five stages (1) familiarising with the data, (2) thematic coding, (3) searching, (4) reviewing themes, and (5) finalising themes (Braun & Clarke, 2006; Clarke & Braun, 2013). Phase 1 involved reading and re-reading transcripts, to understand the data and identify relevant points. Authors met regularly to discuss the transcripts, enabling us to develop consensus in our thinking about coding the data. In Phase 2, initial codes were highlighted in each transcript, using an excel spreadsheet to track and compare codes. Discrepancies were resolved as a team. Phases 3 and 4 involved assembling codes into higher level themes before reviewing the transcripts again to extract any further relevant insights (Supplementary file 2). In Phase 5, final themes were refined, defined and named, by asking: who, what, why, where, when and how questions of the data. Similarly, to Phase 1, the authors met regularly to discuss themes and sub-themes and gain consensus.

# **Findings**

# Sample

We approached the managers of seven nursing homes, all of which agreed to take part. Five were for-profit, and two were not-for-profit organisations. They varied in size from 22 to 70 places. Five were in rural areas and two in urban areas. One (not-for-profit) was rated as outstanding by the CQC, four were rated good and two required improvements.

Twenty-one staff agreed to take part, including: two nursing home managers, one nurse/manager, three registered nurses, four senior care workers, eight care workers, two activity coordinators, and one kitchen assistant. Participants were all female and aged from 20-61 years old. Ethnicity varied including black Caribbean, white British, white European, and Asian backgrounds. Interviews varied in length from 14 to 82 min. Total interview time equated to 14.5 h in total. There were

approximately 28 h of field-notes. Table 1 illustrates nursing home and participant demographics.

# Thematic analysis

Six themes were identified (see Table 2). Four related to how staff engaged with residents with advanced dementia (initiating meaningful engagement, recognising subtle reactions of residents, practising caring behaviour, patience, and perseverance) and two related to when meaningful engagement occurred (lacking time to connect and making the most of time during personal care). These are described in more detail below.

# How nursing home staff meaningfully engage with residents with advanced dementia

#### Initiating meaningful engagement

Nursing home staff said that residents with advanced dementia rarely initiated interactions. Meaningful engagement therefore relied on staff being sensitive to non-verbal signs from residents living with advanced dementia, such as emotional expression, touch, and posture to know when and how to attempt meaningful connections with residents with advanced dementia. This was expressed, for example, in the following two excerpts: 'It's all in their facial expressions, you just need to pay attention' (S02 Senior care worker, NH1 rated as requires improvement). 'She responds with eye contact, not verbally. She occasionally makes little noises and when the noises get louder, I know "Okay you've had enough now" so I will go'. S12 Senior care assistant, NH4 rated as outstanding).

Speaking clearly using short sentences, making eye contact, and giving the resident time to respond were techniques used by staff to meaningfully engage.

Table 2. How and when care workers meaningfully engage with residents with advanced dementia.

Main theme	Subordinate themes
How nursing home staff	Initiating meaningful engagement
meaningfully engage	Recognising subtle reactions of residents
	Practising caring behaviours
	Patience and perseverance
When nursing home staff	Lacking time to connect
meaningfully engage.	Making the most of time during personal care.

Table 1. Participant and nursing home demographics

Participant		Experience working					Nursing			
ID	Role	with older people	Years in home	Ethnicity	Age	Gender	home ID	Setting	Size	Rating
S01	Nurse	4 years	6 years	Black	28	Female	NH1	Urban	31	Requires improvement
S02	Senior care worker	15 years	12 years	White (British)	36	Female	NH1	Urban	31	Requires improvement
S03	Senior care worker	6 years	3 years	White (British)	30	Female	NH1	Urban	31	Requires improvement
S04	Care worker	1 year	1 year	Asian	24	Female	NH2	Rural	34	Good
S05	Nurse	1 year	1 year	White (European)	28	Female	NH2	Rural	34	Good
S06	Care worker	2 years	2 years	Black	31	Female	NH2	Rural	34	Good
S07	Care worker	3 months	3 years	Black	39	Female	NH3	Rural	30	Requires improvement
S08	Activities Coordinator	25 years	12 years	White (British)	61	Female	NH3	Rural	30	Requires improvement
S09	Care worker	2 years	2 years	White (British)	20	Female	NH3	Rural	30	Requires improvement
S10	Kitchen assistant	14 years	14 years	White (British)	52	Female	NH4	Urban	70	Outstanding
S11	Senior care worker	10 years	4 years	White (British)	34	Female	NH4	Urban	70	Outstanding
S12	Senior Care worker	27 years	8 months	White (British)	45	Female	NH4	Urban	70	Outstanding
S13	Nursing home manager	22 years	14 years	White (British)	46	Female	NH04	Urban	70	Outstanding
S14	Care worker	24 years	20 years	White (British)	55	Female	NH05	Rural	63	Good
S15	Activities coordinator	16 years	12 years	White (British)	51	Male	NH05	Rural	63	Good
S16	Care worker	6 years	2 years	White (British)	26	Female	NH05	Rural	63	Good
S17	Care worker	10 years	4 years	White (European)	41	Female	NH06	Rural	69	Good
S18	Care worker	14 years	14 years	White (European)	48	Female	NH06	Rural	69	Good
S19	Nursing Home manager	12 years	12 years	White (British)	43	Female	NH06	Rural	69	Good
S20	Nurse	15 years	15 years	White (British)	38	Female	NH07	Rural	22	Good
S21	Nurse Manager	24 years	4 years	White (British)	48	Female	NH07	Rural	22	Good

Some care workers described using more physical contact than they did with other residents, such as a pat on the arm and/or holding the person's hand.

You know, I speak as slow as I can and try and look into their eyes when I'm doing it, if I can. This one lady she likes it when you stroke her hand, you know, that sort of gets her attention. (S11 Senior care worker, NH4 rated outstanding).

We noted that some of the examples of ways of initiating engagement, which were perceived by staff as successful, could be viewed as contentious. It is possible that speaking extremely slowly, for example, might be received by a person with dementia as being infantilising or patronising (Brooker & Kitwood, 2019).

### Recognising the subtle reactions of residents

An important facilitator of meaningful engagement appeared to be learning to recognise the subtle reactions or behaviours of residents, as in this example of how a member of care staff was seen to understand the way a resident spoke with her eyes: 'Oh she knows Kaz to a tee, she talks with her eyes you see, blink twice for yes, once for no'. (S14 Care worker, NH5 rated good). Knowing each person and paying attention to their reactions was paramount for being able to meaningfully engage. One nurse described how knowing someone's communication habits before their dementia became severe could be helpful: 'You just know, I can't really explain it, I guess you get to know them and as their dementia advances you know what was once normal and what's not and you watch for changes' (S20 Nurse, NH7 rated good).

Another spoke about how developing familiarity with each person over time enabled care workers to recognise the subtle reactions of residents: 'I used to really struggle with Bob. I had a buddy, but we both struggled... You could just tell he wasn't happy, he used to scream when we touched him. It was Terry-Ann that helped us in the end. She told us "He can answer you, look do this" and she showed us what to do to make him calm (S16 Care worker, NH5 good).

Knowing residents, learning their communication repertoire enabled staff to develop their own unique approach to communication with each resident: 'You get to know their ways and quirks, so you have to watch out for different things and learn what they respond to' (S18 Care worker, NH6 good).

# **Practicing caring behaviours**

Staff spoke about the importance of paying attention to their own behaviours in their interactions with residents. They described that the way their body either emphasised or contradicted their spoken words, setting the tone of the interactions. Thus, their actions spoke louder than their words. *Practicing caring behaviours* was therefore described as an essential part of meaningful engagement. Care workers found that approaching residents in a kind, gentle and caring way at a pace that suited the resident resulted in successful engagement with residents. The following care worker illustrates this point. She talks about how her approach to residents with advanced dementia set the tone of interactions: 'It's all about how to approach them. A kind calm approach usually works. They [residents] need to see a friendly face' (\$17 Care worker, NH06 rated as good).

Another care worker reiterated this point. She suggested if staff were not kind or friendly or they did not tell the resident what they were doing, the resident might become frightened which would prevent a connection from being formed:

Well yeah because whenever we are going in to assist somebody, no matter what it is we're doing, we will always say, "Oh we're just going to do this" so they know exactly what we are doing. You know they are expecting it and know what is coming. You get a good response that way. Whereas if we go in and don't tell them what we're doing, then we find that they aren't compliant. They don't work with you and get scared. So, like I say communication is a massive thing and we communicate while we are assisting them, just to give them that bit of stimulation. (S16 Care worker, NH5 rated good)

Other caring behaviours included: greeting a person by name or using nicknames:

'I hear them [care workers] talking to him. One girl goes in and says "Arfur Arfur Arfur" and she can make him giggle sometimes by doing that.' (\$13 Nursing home manager, NH4 rated outstanding)

And it was also seen as helpful for the staff member to give their own name:

I have a tendency of going to this lady's room and I always say, "Hello it is Natalie". It is something I encourage the other members of staff to do, "Hi it is....". It can really make a difference because from the off, the resident knows you're not a stranger. Like this one lady Audrey, she doesn't speak but when I go in and say who it is, she will move her head towards me. I think she recognises my voice...well I think she does. (S12 Care worker, NH4 rated outstanding)

Using humour, or sharing information about their own hobbies or family was also described as fostering engagement:

There was a resident, I think it was this morning, we were just in there and we were talking about, well we were finding a towel or something like that and it is just general chit chat between ourselves [staff], then I said to the resident, "Oh look it's over there" [because I'd already pulled all the bedding out and the covers back looking for it], so I was like, "Ooh look there it is" and tutted haha. I said, "I wouldn't be able to find my head if it wasn't screwed on haha" and she started laughing – so it is just like little bits like that. I just involve them in my conversations no matter what it is about – you know just to get that reaction. (S16 Care worker, NH5 rated good)

A nursing home manager spoke about how she felt a resident acted empathically towards her, enabling her to disclose personal information to her. She recounts that this was beneficial to both the resident and to herself, illustrating a genuine two-way interaction:

There was a lady who I was very close to, who I'd known for many years. She was in the later stages of dementia. Well, I was upset that day, I came to work upset. It was something to do with my father. I tried to keep it to myself, but she [the resident] knew. She absolutely knew without me saying anything at all. She couldn't verbalise that she knew, but I knew she knew because she was patting my leg. She was patting me on my leg, and she was looking at me and I knew, I absolutely knew, that she knew I wasn't myself. I said to her, "Oh you know this has happened" and I sat and talked to her about it. It wasn't against the rules, and I know I made that lady feel useful, I wouldn't do it with everyone, but in this instance it felt right. To share like that can be a positive thing. (S13 Nursing home manager, NH4 rated outstanding)

In considering these caring behaviours, it appears that some could be seen as counter to the expected tenets of person-centred dementia care. For example, the "chit chat" between staff described in the first example could be perceived as excluding residents and the off-loading of a problem in the last example could have burdened the resident. Such behaviours thus appear consistent with the concept of malignant social psychology (Brooker & Kitwood, 2019). Even though staff reported that their

behaviours resulted in positive responses from the residents, this raises a question about the need to pay attention to a resident's reaction or response. Adjusting the content and/or tone of this form of communication could be a first step if there are signs a resident is not comfortable with being talked over or burdened with staff' personal problems.

When asked if she thought caring behaviours made a difference to whether connections occurred, a care worker showed that she empathised with the position of the resident and imagined how she would feel in the person's place:

Oh yes absolutely, definitely. If someone just came at me, I'd be scared, I'd be terrified. You must talk to people. You can't just go in and do something to someone, you must talk to them, especially if they can't talk to you. You've got to go spend time with that person and look for a sign that they are happy for me to do it. If they aren't then they will pull away or they will grab if they didn't like it. So, with this lady if she didn't want me to do her nails, then she'd grab or she would pull her arm away - but she didn't. She just sat there and let me do it and she was nearly asleep. (\$16 Care worker, NH5 rated good)

However, despite paying attention to residents' reactions and practising caring behaviours, staff expressed that they could not always connect despite their best efforts:

Sometimes with people living with dementia you struggle on and you struggle on. You try hard to engage, to get that person to smile or be calm if somebody is heightened. It is wonderful when it does work, but you also have to understand that the very nature of their illness means that sometimes it won't or it's hard to understand if and when they do. (S13 Nursing home manager, NH4 rated outstanding)

It was still seen as vital to go on trying however: 'You can talk to them and give them a full lunch and they won't even open their eyes. They will literally just eat with their eyes closed and not react whatsoever...you've just got to keep going' (S12 Care worker, NH4, rated outstanding).

Patience and perseverance were therefore key to engaging in those special moments of connection.

# Patience and perseverance

When unable to get a response, some staff described going back repeatedly to a resident until they formed a connection:

I think it was pester power. I just kept going and going to her room and I got nothing and then one day [I always used to go to see if she wanted her nails doing and never got anything that I recognised as a response] and then one day I just picked her hand up and said, "I am going to do your nails" and she just looked at me and smiled and I was like "Ooh great" but it was months and months'. (S07 Care worker, NH3 rated requires improvement).

This persistence was underpinned by the care workers' convictions that there was a person to connect with: 'It's about not giving up and knowing that there is someone in there. It's up to us as carers to bring them out' (S12 Senior care worker, NH4 rated outstanding). It was rewarded by responses from the residents, even when these were slight. One senior care worker indicated that knowing what to look for, was important: 'There are little clues sometimes, you just have to notice the signs with them' (S13 Senior care worker, NH4, rated outstanding). When asked for an example she said:

Yes, with the first lady we were talking about before, there was something on the television. I can't remember what it was but she was watching it and I happened to say something about it and her eyes just lit up and she gave me a little tiny grin and I went, "Ooh okay" and I carried on talking about whatever it was and that to me was everything, because I thought, "Ooh I've got through", I've made that little bit of a difference, you know she is interested in whatever this particular item on the TV was. I mean I don't bring it up all the time because it's not always on the TV. I try to sort of do day-to-day things when I am talking to her depending on what is going on at the time, but that particular item she was sort of like engaging and to me that was really good because I thought we are on a winning line here and I did talk to her about it for a good few minutes and then she just closed her eyes and went to sleep (S12 Senior care worker, NH4 rated outstanding).

Many staff suggested that by doing this they learned small details about a resident. This was described as making the difference to the level of connection during an interaction:

This is where the knowing someone comes in handy because I was chatting to him about boats. He used to be a sailor so I used to talk about going on boats and would ask if he enjoyed being out at sea and stuff like that and he would occasionally say yeah, or once when I was talking, he came out with "What are you talking about" and I was quite taken aback by that. I was just waffling away to him about boats and he just turned and looked at me and said, "What are you on about?". He wouldn't normally say anything. On this occasion I knew he'd only just had his pain killers so he would be pain free for a while, so I took the opportunity to sit down and chat to him. I gave him some chocolate mousse as well then just talked to him about boats – well until he told me to shut up – haha. (S12 Care worker, NH4 rated outstanding)

Some care workers, however, were reported as not persevering:

I've seen it before where I have seen someone go to talk to somebody and there wasn't really time spent. They went over and said, "How are you today" and then maybe said, "Oh I am doing this, and I am doing that" but there was obviously very little reaction. I could see that he probably was listening, but there wasn't an obvious reaction, so it didn't take very long for that person [staff] to get up and they left and they went to speak to somebody else. (S13 Nursing home manager, NH4 rated outstanding)

Those who gave up described not thinking there was a person to connect with. They did not describe practicing caring behaviours or give examples of where they had connected: 'With the advanced, I don't think they really know we're there half of the time. It's not their fault of course' (S07 Care worker, NH3 rated as requires improvement).

Whilst we report examples seen as positive by care staff interviewed for this study, similarly to other themes, we note the potential of behaviours associated with patience and perseverance to intimidate, impose on or disparage residents.

# When nursing home staff meaningfully engage with residents with advanced dementia

### Lack of time to connect

Whilst initiating meaningful engagement, recognising residents' actions/reactions, practicing caring behaviours and patience and perseverance, facilitated meaningful engagement, having the time to connect with any resident, let alone with residents with advanced dementia was a key concern for staff in this study:

Unfortunately, with the pressures of the job you don't even get time to do what you need to do, let alone spend time with individual people and that's what you need to do with people who can't



communicate. Time, it is so rewarding when you get a positive reaction but the more rushed you are, the more intimidating you're being by being in a hurry. (S17 Care worker, NH6 rated as good.)

Every day in a nursing home was described to be different. Planning a specific time to connect with residents with advanced dementia on any given day, was challenging even where it had previously been planned:

It really is a challenge to get that one-on-one engagement sometimes, mealtimes especially because it is the busiest time. We see it as a time for one and one interaction, but I must be honest it doesn't always work like that, but that is what we are trying to get to. (S13 Nursing home manager, NH4 rated outstanding)

While many staff wanted to form connections, they felt they were constantly constrained by having other tasks to do and having other residents to attend to. This left them with little time and flexibility within their role to form connections with residents with advanced dementia:

The only thing that stops me is the lack of time. I'd quite happily sit and read a book or draw pictures or do whatever they like to do, just to see their reaction, but I don't have time...we only really see them during personal care. (S06 Care worker, NH2, rated good).

Indeed, the dependency of residents living with advanced dementia meant that meeting their physical needs demanded a lot of time. Staff often got caught up in the very basics of care: 'We don't get time to do anything else other than personal care' (S07 Care worker, NH3 rated requires improvement).

#### 'Making the most of time' during personal care

Some staff suggested they resolved their main concern of "struggling to find time" by "making the most of time" during personal care. For them, personal care was considered an optimal time to connect.

We're washing them, feeding them dressing them, multiple times a day, you know we're here anyway, why not make it fun and enjoyable as much as we can. I get a real kick out of making someone's day better, I mean it's easier with those you can speak too, but there is a particular kick when you get a smile, a giggle, a grin, it means everything. (S12 Care worker, NH4 rated outstanding).

The way staff used their time during personal care was important for whether connections occurred:

I think when you're doing personal care and you're talking and you're involving her, even though she is not with us, well she is with us, but you know what I mean. She might not understand or follow the conversation, but she is still a part of it. So, we were talking, and she laughed. She was laughing at us. I said to the other person, "Oh look, she is laughing". So, I said, "Are you laughing?" and her facial expressions said yes. (S18 Care worker, NH6 rated good)

Staff who made the most of time made thoughtful adaptations to their daily personal care routine to incorporate time for meaningful engagement:

Well, it's all about multi-tasking if I'm totally honest with you. Getting them up and dressed, turning them and eating is maybe the only time we'll see them [residents with advanced dementia]. If you can do something they like in that time, then that helps you as a carer [as they are more compliant], but actually it's good for them n'all cos they get that little bit of stimulation (S11 Care worker, NH4 rated outstanding.)

Some staff sang to residents, danced for residents, and used their favourite lotions, scents and cleaning products as props

to assist them in meaningful engagement during personal care: 'I have a habit of getting one of her little toys and I dance with it at the end of the bed. I am a bit mad, and it makes her laugh' (S07 Care worker, NH3 rated as requires improvement).

These approaches were described to be spontaneous, unstructured and ad hoc:

I mean I don't do that [sing] all the time, it depends on what I'm doing, or what the resident will respond to, so I change it up and do whatever I need to get a reaction. It's like you need a toolbox of things to try (S21 Nurse manager, NH7 rated good)

Throughout the findings we have highlighted the fine line between perceived positive interactions and social behaviours that could undermine personhood. This also applies to this section 'making the most of time'. A care worker describes 'washing, dressing and feeding them', which implies doing to rather than with i.e. objectifying. Another care worker implies the resident does not understand or follow the conversation, implying invalidation. Finally, a care worker describes doing things to make the resident more compliant which suggests imposition (Brooker & Kitwood, 2019).

Staff were clear that there was not a single approach to connecting with residents with advanced dementia. Those who could adapt, try new things and come back later were most able to describe connections. This relied on initiating meaningful engagement, recognising subtle reactions, practising caring behaviours, being patient and making the most of time during personal care.

#### Discussion

Initiating meaningful engagement, paying attention to the subtle reactions of residents, such as eye contact and facial expressions, practicing caring behaviours, and having patience and perseverance were identified as important for how nursing home staff meaningfully engaged with residents with advanced dementia. The dependency of residents and the complex and dynamic nature of the nursing home environment; however, meant that care workers often struggled to find the time to do these things. Fifteen of the 21 care workers we spoke to suggested they resolved their main concern of 'struggling to find time', by 'making the most of time' during personal care. For them, personal care was considered an optimal time to connect. This suggests staff members who believe there is still a person to connect with and perceive it is part of their role to connect, adapt their behaviour to successfully engage with residents with advanced dementia during personal care.

The care workers' accounts of how they achieved meaningful engagement can be interpreted using the lens of person-centred dementia care. Kitwood (1997) introduced the concept of positive person work, to embrace a number of dimensions of interaction that supporters of those with dementia can employ to support the personhood of people with dementia, including recognising, validating, negotiating, and playfulness. All these dimensions were described by staff as they recounted their experiences of meaningful engagement with residents. For example, staff talked about looking for subtle signs a person wanted to connect [recognition], the importance of getting to know residents and their life stories [validation], giving the person time and space to respond and persevering when they did not get a response [negotiating]. Staff also described using humour and jokes to meaningfully engage [play]. Knowing the

person was a key part of positive person work. In almost all the examples given the care worker knew the residents well. Those new to care work or the care home often struggled to think of examples of where they had connected. Knowing the person is an essential part of person-centred dementia care and a key part of interventions to implement it (Rapaport et al., 2017).

Kitwood (Brooker, 2019) also outlined aspects of interaction that undermine personhood and well-being, terming these malignant social psychology. A number of dimensions of malignant social psychology were described by interviewees when talking of seeing others failing to establish meaningful engagement, for example, ignoring, outpacing, and banishment of residents. Our themes were inductively derived from carers' subjective accounts without a preconceived theory in mind, yet the descriptions reflect key dimensions of positive person work and malignant social psychology. This interpretation of our findings therefore adds validation to the theory of person-centred dementia care.

The findings do, however, highlight contradictions between some of the examples care staff saw as positively promoting connections and some of the accepted tenets of person-centred dementia care. Although certain ways of connecting were perceived by care workers as positive, they could be interpreted as undermining personhood by infantilising, objectifying or ignoring the person (Brooker & Kitwood, 2019; Kitwood, 1997). It could be that the accepted dimensions of positive person work and malignant social psychology have been drawn from a culturally narrow base and need revision to be more embracing of a wider range of sub-cultures, for example, across socio-economic groups, or it could be that some aspects of what staff perceive as positive would undermine personhood over time. This suggests that there should be further research on the impact for people living with dementia of some of the approaches we found around how to connect before these strategies are promoted as good care practice.

Our findings suggest personal care as an optimal time to connect. Care workers described their real-world struggles of not having time to connect with people with advanced dementia because of the demands of their work. In this way, they did not need extra time but found a way of capitalising on times of personal care, when they were inevitably spending time close to a resident. Several studies echo our findings that personal care is a good time to connect (Colomer & de Vries, 2016; Edvardsson et al., 2014; Hammar et al., 2011; Kemp et al., 2021; Rapaport et al., 2017; Watkins et al., 2017; Watson, 2019). Using brief intimate interactions to promote personhood and creating bonds during routine interactions have been widely reported (Colomer & de Vries, 2016). Rapaport and colleagues found that spending time talking to residents about their likes, dislikes, showing them photos, singing, or helping residents to put on their jewellery did not entail much more time and often made personal care more enjoyable all round (Rapaport et al., 2017). Also resonating with our findings, singing during personal care has been cited as a way of encouraging expressions of emotion and reducing resistance (Hammar et al., 2011). Humming in particular is a potential tool for facilitating mealtimes for persons with dementia (Watkins et al., 2017; Engstrom & Hammer, 2012).

Our themes on how care staff meaningfully engage seem to echo many of the attributes of therapeutic touch and multi-sensory stimulation interventions described in the introduction of this article. Touch is a core aspect of care provision and therapeutic relationships. Therapeutic touch allows the care worker to initiate meaningful engagement and negotiate therapeutic relationships. This is achieved through touch or non-touch by maintaining

channels of communication often lost in dementia as the disease progresses (Doherty et al., 2006). The Namaste care intervention (Simard & Volicer, 2010) focuses on enhancing the atmosphere around personal care to foster well-being for people with advanced dementia (Bunn et al., 2018; Simard & Volicer, 2010; Smaling et al., 2018; Stacpoole et al., 2015, 2017). The intervention involves multi-sensory stimulation such as: lowering lights, using relaxing scents, and playing music to create a calm, distraction-free environment, and therapeutic touch. Staff offer loving touch when greeting and washing residents, moisturising skin, and combing/brushing hair. Qualitative findings suggest Namaste has a positive impact on residents with advanced dementia who speak, smile, and interact more; and over became more comfortable with being touched, showing less resistance to personal care (Magee et al., 2017; Mcniel & Westphal, 2018; Stacpoole et al., 2017). A realist review suggested Namaste care provided regular, structured access to social and physical stimulation, equipped staff with the skills to work with people with complex behaviours and provided a framework for person-centred dementia care (Bunn et al., 2018). Thus, both our findings and the practice of Namaste care show enactment of person-centred dementia care principles. The care workers in our study were using person-centred dementia care informally, having learnt by trial and error what worked to establish meaningful engagement but without knowing anything about the underlying theory. By recognising and formalising what care staff are already doing, the Namaste approach could be helpful in validating and extending their delivery of person-centred dementia care.

However, our findings also raise concerns about the sustainability of Namaste care in practice. Staff in our study said they meaningfully engaged in ad hoc ways, mostly during personal care, because of the lack of time they had available. Namaste is a structured intervention delivered through specific sessions, so the time requirement is likely to be a barrier to embedding it in practice. This may explain the findings of one study, in which there was an increase in distressed reactions from residents, attributed to poor leadership and inadequate staffing (Stacpoole et al., 2015, 2017). It seems vitally important that attempts to improve well-being through enhancing person-centred dementia care take into account the scarce time and staff resources of the nursing home context.

Taking into account the experiences of care workers tasked with delivering person-centred dementia care is essential if interventions are to be implemented in practice. This issue is reflected in the broader person-centred dementia care literature which suggested researchers have often placed more emphasis on effectiveness than implementation of interventions and have rarely sought the views of nursing home staff (Qiu et al., 2019).

# Implications for research

This exploratory study illustrates that care workers are intuitively using person-centred dementia care principles in their daily practice, having learnt from their own day-to-day experiences. In this context, formalised training consonant with the best aspects of nursing home staff's existing practice, would seem to be a possible vehicle to validate good practice and spread it more widely. We suggest a participatory approach to developing an adapted/tailored version of Namaste care, promoting meaningful engagement with residents with advanced dementia, without taking extra time and resources would be a useful line of future research. We noted above that some of the examples of how staff connect could

be considered as undermining rather than promoting personhood. With this in mind, further research could look further at the sorts of examples given and their acceptability to people living with dementia and their families.

#### Implications for practice

Personal care is often overlooked as an opportunity to connect (Kemp et al., 2021). In our study, residents were described as having more frequent meaningful interactions when staff viewed each encounter as having potential for meaningful engagement. Small changes in care workers' everyday routines can be implemented immediately at little cost and disruption. Emphasising to staff the importance of getting to know residents, learning their communication patterns and using every opportunity as a chance to connect, and making it clear that this is recognised as a core part of their role, could improve meaningful engagement.

#### Limitations

While interviews generated rich, in-depth descriptions of care, they were reliant on staff self-report. Observations could have made the study more robust. However, as most of the interactions occurred in residents' bedrooms during personal care, observation would have been intrusive and was deemed not ethically appropriate. Instead, the lead researcher supplemented formal interviews by spending time in the nursing homes, informally chatting with staff, including immediately after they had performed or observed personal care to get examples of the times they had connected. Care homes were purposively selected to gain variation and to include care homes known to the lead researcher where best practice had previously been observed. This will have led to some bias in findings, though it also enabled us to gain examples of how and when connections were formed.

#### **Conclusion**

This study highlights the importance of care workers' perceptions of connecting with residents with advanced dementia. Care workers did not talk explicitly about using person-centred dementia care principles to help them to meaningfully engage, however, their approach embodied many aspects of person-centred dementia care. Staff also emphasised personal care as an optimal time to engage with residents. Lack of staff time militates against the implementation of formal interventions in nursing home settings. However, understanding the resonance between how and when care workers meaningfully engage with residents with advanced dementia, Namaste care and person-centred dementia care, suggests a way forward for improving care. We suggest adapted Namaste care could be used by nursing homes to formalise, recognise, and further develop staffs' intuitive practice. Participatory approaches which include the practical wisdom of staff in designing interventions to promote meaningful engagement with residents with advanced dementia during personal care are essential.

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The authors report there are no competing interests to declare.

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# **Data Availability statement**

The data that support the findings of this study are available from the corresponding author, [KH], upon reasonable request

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