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# Older peoples' lived experiences of personalised care in care homes: A meta-ethnography

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## Abstract

**Background:** Guidance and policy on personalised (or person-centred) care of older people living in care homes advocates that all residents must have their preferences considered, and that all care provided must be reasonably adjusted to meet the person's specific needs. Despite this, research that considers what matters to residents in terms of the care they receive is limited.

**Objectives:** Our review aims to explore care home residents' lived experiences of personalised care and understand what really matters to them.

**Methods:** Six electronic databases (CINHAL, Medline (Ovid), Embase, PubMed, Web of Science & PsychInfo) and Google Scholar (grey literature) were searched to identify qualitative studies relating to personalised care in care home settings, which also included resident (voices) quotes. The literature review and synthesis are reported using eMERGe guidance.

**Results:** Fifteen studies met the inclusion criteria for our meta-ethnography. Four conceptual categories (the challenge of fitting into institutional care, the passing of time, holding onto a sense of self and a desire to feel at home) and two key concepts (creating a culture of purposeful living and caring and forming and maintaining meaningful & empowering relationships) were identified. Finally, a conceptual framework of understanding represents what personally matters to residents in terms of their care.

**Conclusion:** Our meta-ethnography, guided by residents' lived experiences of personalised care, offers a new perspective of what personally matters to residents in terms of the care they receive. The conceptual framework of understanding highlights the importance of moving from an institutional position of doing for residents to a person-centred position of doing with residents.

**Implications for practice:** Our findings highlight the importance of understanding the differences between personalised and person-centred care for policy and practice. Further considerations are required on how this might be applied through nurse and care home professionals' education and work practices.

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## KEYWORDS

care homes, care professionals, nurses, personalised, person-centred, residents

## 1 | INTRODUCTION

There are an estimated 2.9 million residents living in 43,000 long-term facilities in Europe representing 0.7% of the total EU population (European Centre for Disease Prevention and Control (ECDC), 2021). Similarly, in the UK, more than 400,000 people are living in just over 17,000 care homes (Office of National Statistics (ONS), 2021; Munson, 2022), (0.6% of the UK population (ONS, 2023)). Most residents' receiving care in residential and nursing care homes are older people living with dementia, frailty and end-of-life care needs (British Geriatric Society (BGS), 2021; Organisation for Economic Co-operation and Development (OECD), 2021; Yuan et al., 2021).

Over 750,000 care home professionals, nurses and support staff provide the care across a variety of residential, nursing and mixed provision settings in the UK (Munson, 2022). In the UK, 42% of care homes provide nursing care (BGS, 2021). All UK registered care homes are required to follow a set of national quality and safety standards and regulations, including personalised or person-centred care practices (Care Inspectorate, 2019; CQC, 2022; RQIA, 2021). This requires that all people using care home services must have their preferences considered, and all care must be reasonably adjusted to meet the person's specific needs. This requirement is also a central tenet of the Enhanced Health in Care Homes Framework (EHCH v.2) (NHS England/NHS Improvement (NHSE/NHSI), 2020) embedded within England's NHS Long-Term Plan (NHS England, 2019) and the British Geriatric Society's Ambitions for Change: Improving health-care in Care Homes Document (BGS, 2021).

Despite UK policy, practice guidance, and national minimum standards of (care home) care (DH, 2006) championing personalised/person-centred care for many years, implementation has been somewhat complicated by the subjective and diverse descriptors ascribed to the terms (Ettelt et al., 2020; Task Force for the Future of Residential Care in Scotland, 2014). Indeed, personalised and person-centred care are often used interchangeably with similar descriptors such as personal choice, shared decision-making, inclusivity, control and consent, seeing the individual, and respecting and utilising personal strengths (Department of Health & Social Care (DHSC), 2021; NHS England, 2016; NHS England, 2017; NHS England, 2019). However, personalised care tends to focus on what *can be done for the person* to remain safe and well, whereas person-centred care considers what is *uniquely important to the person* themselves (Gadd & Cronin, 2018). Person-centred care can be seen as an approach to care that places an emphasis on listening to and *doing with* the person, whereas personalised care practices place an emphasis on *doing for* the person and wider care community (The Health Foundation, 2016). Both terms will be used and applied to the search strategy, analysis and the final synthesis due to their interchangeable use across policy, practice and research. However, we

## Summary statement of implications for practice

## What Does this Research Add to Existing Knowledge in Gerontology?

- The meta-ethnography shares a new conceptual framework for understanding what personally matters to residents in terms of the care they receive in care homes.
- The meta-ethnography highlights scope for further international research on the challenges faced in providing person-centred care in residential and nursing care home settings.

## What are the Implications of this New Knowledge for Nursing Care with Older People?

- The meta-ethnography highlights the importance of nurses and other care home professionals practising in ways that promote the older peoples' agency, autonomy and personhood.
- The meta-ethnography recognises and shares the importance of purposeful care cultures and meaningful relationships in supporting the emotional and physical wellbeing of older people in care.

## How Could the Findings be Used to Influence Policy or Practice or Research or Education?

- The meta-ethnography highlights the importance of understanding the differences between personalised and person-centred care in policy and practice and how this might be applied through nurse and care home professionals' education.
- The meta-ethnography highlights the absolute importance of capturing and representing the voices and experiences of all older people when considering developments in practice, policy and education.

will explore the juxtaposition of the two terms further in the discussion section and their implications to policy, practice and research.

The meta-ethnography focuses on studies that have been published in the last 10 years. However, research on what personally matters to residents in terms of their care, and personalised models and frameworks used in care home settings precede this. There is a body of earlier work that concludes that residents' priorities tend to include freedom of movement, meaningful social engagement

TABLE 1 PEO keywords and search terms.

Population	Exposure	Outcome
Old* (Older)	Person cent* ( <i>Person-centred, Person-centered</i> )	Opinion
Adults	Personal* ( <i>Personalised, Personalized</i> )	View
People	Individual* ( <i>individualised, Individualized</i> )	Perspective
Persons	Care	Perception
Elder* (Elderly)		Experience
Resident*(s) (Residential)		
Nurs* (Nurse(s), Nursing)		
Long (-) Term		

and caring practices and yet managers and care professionals' priorities are often the health and safety of their residents and the challenges of resource constraints (Bradshaw et al., 2012; Popham & Orrell, 2012). Similarly, early person-centred researchers suggest that personhood and relationships are key factors of a creating a personalised care culture (Kitwood, 1997; McCormack et al., 2012).

Recent international research focusing on the concept of personalised care or person-centred care in care homes has predominantly sought to explore it from the perspective of those providing the care, rather than those receiving it (Backman et al., 2019; Lood et al., 2021; Vassbø et al., 2019). Studies that have considered care home residents' lived experiences of personalised care have tended to focus on specific personalised approaches, including narrative-based approaches (Buckley et al., 2018) or interventions such as music (Kuot et al., 2021). Alternatively, they represent aspects of care, such as social contact, diet, sleep or bathing (Abbott et al., 2018; Kusmaul & Tucker, 2020), rather than the whole of a resident's care experience. Other resident-focused studies have considered quality of care and life (Johs-Artisensi et al., 2020; Milte et al., 2016; Moyle et al., 2015). This included a systematic review on residents' perspectives of quality of care (Gilbert et al., 2021) which found that although residents' experiences varied, insufficient staffing, high turnover and a lack of training were factors that inhibited the potential of quality of care.

Our meta-ethnography will not explore one aspect of personalised care, single intervention, or measure of quality, but instead aim to understand what personally matters to residents in terms of the care they receive. It also aims to address a gap in research by using meta-ethnography to review relevant international qualitative research to formulate a conceptual framework of understanding that represents what personally matters to residents in terms of the care they receive.

## 2 | METHODS

A principal aim of meta-ethnography and the meta-ethnographer(s) is to derive meaning across a small but diverse qualitative data set (Sattar et al., 2021). As a methodology, it uses inductive and interpretative approaches to synthesise selected studies to express a conceptual understanding of a phenomenon (Soundy & Heneghan, 2022). It does so by preserving the selected studies

meaning and context (France et al., 2019b), while also acknowledging, and where possible raising the voices of the research participants (Everhart & Johnston, 2018).

The meta-ethnography is completed and structured according to the seven-phase eMERGe Reporting Guidance (France et al., 2019a) and the seven-step process for conducting a meta-ethnography developed by Noblit and Hare (1988). This method provided us with a systematic process in which to explore what personally matters to residents in terms of the care they receive.

Noblit and Hare (1988), in their seminal work, suggested that the synthesis of data should be in the form of a reciprocal or refutational translation, or a separate Line of Argument (LOA) synthesis. This would determine if there were comparable (reciprocal) or opposing (refutational) findings across the selected studies (France et al., 2019b), or in the case of a LOA synthesis, the construction of an overall argument about what the studies said (Thorne et al., 2004). However, it is now common practice in meta-ethnography for a combination of the three syntheses to take place (France et al., 2019b).

Our meta-ethnography will present a reciprocal translation displayed as key concepts and a LOA synthesis in the form of a conceptual framework of understanding. This will offer a greater understanding of what personally matters to residents in terms of the care they receive. This new understanding (third-order construct) is achieved through the analysis, translation, and synthesis of direct resident quotes (first-order constructs) and the themes and interpretations of the selected studies (second-order constructs).

### 2.1 | Search strategy

The first reviewer (GH) completed a comprehensive literature search across six relevant bibliographic databases (CINHAL, Medline (Ovid), Embase, PubMed, Web of Science & PsychInfo) of studies dated between December 2012 and December 2022. A PEO (Population, Exposure and Outcome) framework (Khan et al., 2003) identified keywords and search terms (Table 1).

The search strategy included Boolean operator combinations and truncation symbols (Table S1). Citation chaining was completed on all eligible studies, alongside a grey literature Google Scholar search.

## 2.2 | Inclusion and exclusion criteria

Published studies were included if they met the following criteria:

1. Relevance: Studies published in the last 10 years (December 2012–December 2022) for application to current policy and practice.
2. Focus: Studies focused entirely on what personally matters to residents in terms of the care they receive, rather than 'quality' (of care/environment/life) or specific approaches, interventions or topics.
3. Setting/Population: Studies needed to involve the experiences/voices of older people (>65) residents in care home settings. Mixed sample/participant groups were included if older peoples' (resident) voices were represented.
4. Study type/design: qualitative method of data collection/analysis. This included mixed method studies if a qualitative component was significant and relevant.
5. Specific: Only English written studies were included.

## 2.3 | Study selection and outcome

The first reviewer (GH) removed duplicates, leaving 1509 studies to be screened title /abstract reviewed against the inclusion and exclusion criteria. Of these, 36 studies were eligible for an independent full text review by two of the reviewers (GH & SP) to reach an

inclusion consensus. In total, 15 studies met the inclusion criteria for the meta-ethnography. See the PRISMA flow diagram (Moher et al., 2009) for full details of the study selection process and search outcome (Figure 1).

## 2.4 | Quality appraisal

A CASP qualitative study checklists (CASP, 2021) was completed against all 15 selected studies by two of the reviewers (GH & SP) (Table S2). There is often difficulty in establishing (Question 10); 'how valuable is the research?' (CASP, 2021), as many CASP questions consider methodological rigour rather than measuring its conceptual strength (Toye et al., 2014). Therefore, numerical scores were not used as a measure of methodological quality (Sattar et al., 2021).

There is a growing consensus amongst meta-ethnographers that conceptual richness and/or an overall contribution to the final syntheses are more important than critiquing methodological robustness (Campbell et al., 2011; France et al., 2014). Noblit and Hare (1988) also argue that the quality of a paper should be judged by the conceptual contribution that it lends to the overall synthesis. Following a comparative discussion of the 15 selected study's findings, the quality reviewers (GH & SP) agreed that all studies were conceptually and/or descriptively rich enough (France et al., 2019b; Toye et al., 2014) to contribute towards the data translation and final synthesis; therefore, all were included.

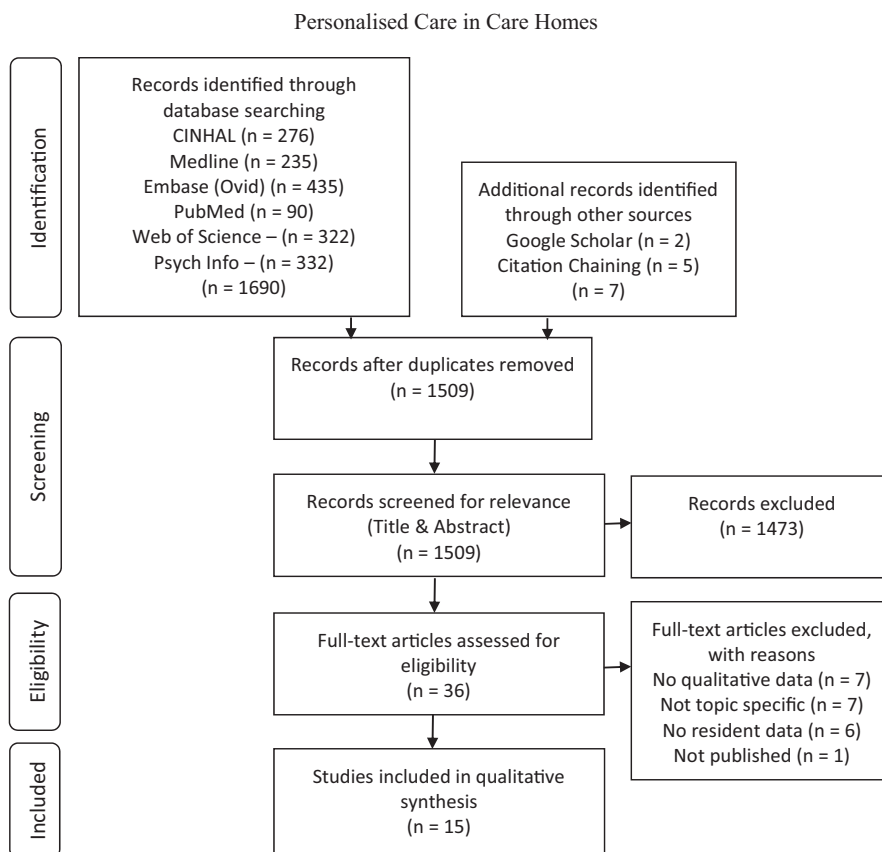


FIGURE 1 Prisma flow diagram.

## 2.5 | Data abstraction

Data from the 15 selected studies were abstracted under the following headings: author(s), data collection method, data analysis method, sample/setting, participant characteristic, purpose of study, inclusion criteria met and whether resident input (voices) was present (Table S3). The sharing of the data abstraction table allowed for further discussion between all reviewers (GH, IL, RB & SP) and offered clarity to how an inclusion consensus was achieved.

## 2.6 | Descriptive characteristics of included studies

Most studies took place in Norway (Drageset et al., 2017; Dybvik et al., 2014; Mjørud et al., 2017; Nygaard et al., 2020), Australia (Ludlow et al., 2021; Minney & Ranzijn, 2016; Walker & Paliadelis, 2016), and the US (Bangerter et al., 2016; Harrison & Frampton, 2017), with only one study taking place in the UK (Cook et al., 2015). Twelve of the studies excluded residents with dementia, with only three studies including residents with a known dementia diagnosis (Harrison & Frampton, 2017; Mjørud et al., 2017; Nygaard et al., 2020). Fourteen studies used interviews for their data collection. One (Harrison and Frampton (2017) used only resident focus groups. Study samples size ranged from six participants (Dybvik et al., 2014) to 337 participants across 35 nursing homes (Bangerter et al., 2016). All 15 studies included resident voices through verbatim quotes.

## 3 | ANALYSIS

### 3.1 | Data translation and synthesis

The first reviewer (GH) re-read all 15 selected studies before the process of study relationships and translation began. Participant verbatim quotes (first-order constructs), study interpretations (second-order constructs  $n=50$ ) and study themes ( $n=60$ ) were abstracted from the studies and transferred into a constructs table (Table S4). This table was used to support data translation and synthesis. All data recorded on the constructs table was also uploaded to NVivo version 12 Pro (QSR, 2018) software. Using these two methods of data management offered differing forms of visual data representation and organisation. It also validated the process of construct comparison and translation by matching software coding with the initial manual coding completed on first reading the studies (Welsh, 2002).

Reading the studies and reviewing the data in the constructs table (quotes, themes and interpretations) allowed comparison to take place determining if and how the studies were similar or related (reciprocal). To do this, relevant text and phrases were highlighted in bold across the selected study's themes and interpretations within the constructs table (Table S4), and colour-coded across the data in NVivo version 12 Pro (QSR, 2018).

Indicative quotes taken from the primary order constructs were also highlighted (Table S4) and used in the findings section. The first reviewer (GH) screened the texts and phrases for similarities, patterns, and relationships. This confirmed that a reciprocal translation and a LOA synthesis (conceptual framework of understanding) were possible. The outcome of this initial screening was checked by a second reviewer (SP) for reliability.

Translating the studies into one another began by combining similar (bold or colour coded) text and phrases. This required a multi-layer interpretative process of mapping (Chandler et al., 2015) which concluded with four conceptual categories (the challenge of fitting into institutional care, the passing of time, holding onto a sense of self and a desire to feel at home). Although these four conceptual categories had begun to translate findings and make relationships across the data, they had not yet generated a conceptual understanding or meaning (Cahill et al., 2018; Noblit & Hare, 1988). This required a higher order interpretation (Noblit & Hare, 1988).

Toye et al. (2014) state that one of the principal aims of qualitative analysis is to develop concepts that help the reader understand an experience rather than purely describe it. The process of key concept development (reciprocal translation) was conducted by two of the reviewers (GH and SP). They remapped the second-order constructs and four conceptual categories to produce two overarching key concepts of understanding and meaning (creating a culture of purposeful living and caring; forming and maintaining meaningful and empowering relationships) and achieved a reciprocal translation across the 15 selected studies, displayed in the key concepts table (Table 2). Finally, to express this synthesis, the reviewers (GH and SP) produced a LOA synthesis that combined the conceptual categories and key concepts. The LOA presents a conceptual framework of understanding (Figure 2) that represents what personally matters to residents in terms of the care they receive.

Reviewer one (GH) shared the conceptual categories, key concepts and the conceptual framework of understanding with all the other meta-ethnography reviewers (IL, RB & SP) opening a space for discussion, challenge and modifications (Toye et al., 2013) as well as ensuring rigour and transparency. This sharing and discussion of conceptual findings led the placement of the resident at the centre of the new conceptual framework of understanding. At all times, the interpretative building blocks of the conceptual framework maintained a direct and visible connection with the selected study participants' voices (first-order constructs) and the studies authors' interpretations (second-order constructs), as required in any meta-synthesis (Britten et al., 2002).

## 4 | FINDINGS

We have used resident voices (indicative quotes) throughout the findings section to offer authenticity and to display the synergy between the first and second-order constructs and the conceptual

TABLE 2 Key concepts table.

Key concepts	Conceptual categories	Examples of text & phrases which contribute to concepts	Studies that support the concepts
Creating a culture of purposeful living and caring	The challenge of fitting into institutional care	'confined and institutionalised', 'choice and control', 'routine tasks', 'constrained by routine', 'not personalised', 'viewed as a lower priority', 'acceptance and adaption', 'independently set day's agenda', 'institutional tendency', 'resigned acceptance', 'institutional rules and regulations'	Cho et al., 2017; Chuang et al., 2015; Donnelly & MacEntee, 2016; Dybvik et al., 2014; Harrison & Frampton, 2017; Ludlow et al., 2021; Minney & Ranzijn, 2016; Nygaard et al., 2020; Palacios-Ceña et al., 2013; Walker & Paliadelis, 2016; Wang et al., 2016
	The passing of time	'interpersonal interactions', 'growth & leisure activities', 'talking about death', 'engaging in & lacking meaningful activity', 'significant time alone', 'wish for other relationships', 'waiting long periods', 'rhythm of the day', 'significant activities were meaningful', 'time in the facility was finite'	Bangerter et al., 2016; Cho et al., 2017; Chuang et al., 2015; Cook et al., 2015; Drageset et al., 2017; Dybvik et al., 2014; Ludlow et al., 2021; Minney & Ranzijn, 2016; Harrison & Frampton, 2017; Mjørud et al., 2017; Nygaard et al., 2020; Walker & Paliadelis, 2016
Forming and maintaining meaningful & empowering relationships	Holding onto a sense of self	'self-dominion', 'limited autonomy', 'choice and control', 'construct their lives', 'disengaged', 'individualised influence', 'everything is gone', 'make their own decisions', 'sense of identity', 'individualism overlooked'	Bangerter et al., 2016; Cho et al., 2017; Chuang et al., 2015; Cook et al., 2015; Donnelly & MacEntee, 2016; Harrison & Frampton, 2017; Mjørud et al., 2017; Palacios-Ceña et al., 2013; Walker & Paliadelis, 2016; Wang et al., 2016
	A desire to feel at home	'wanting to feel at home', 'feel safe/secure', 'establish a 'home', 'accept the loss', 'old homes', 'a real home', 'being at home', 'more like a home', 'never return home'	Bangerter et al., 2016; Cho et al., 2017; Chuang et al., 2015; Cook et al., 2015; Dybvik et al., 2014; Minney & Ranzijn, 2016; Mjørud et al., 2017; Nygaard et al., 2020; Palacios-Ceña et al., 2013; Walker & Paliadelis, 2016

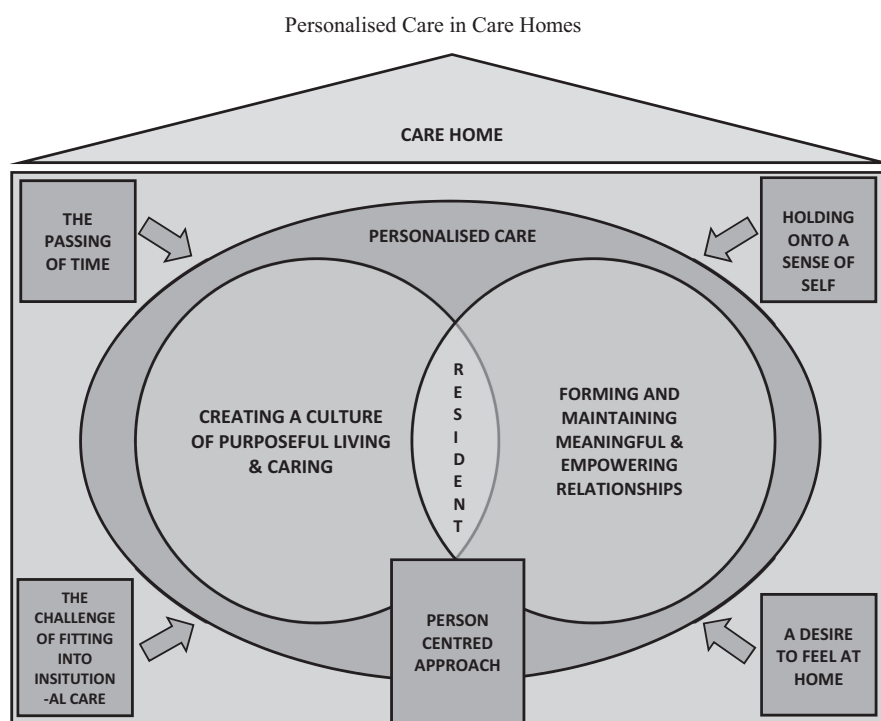


FIGURE 2 Conceptual framework of understanding.

findings of the meta-ethnography. Findings are initially presented through four conceptual categories (the challenge of fitting into institutional care, the passing of time, holding onto a sense of self and a desire to feel at home) and two key concepts (creating a culture

of purposeful living and caring; forming and maintaining meaningful and empowering relationships). Finally, the LOA synthesis offers a conceptual framework representing what personally matters to residents in terms of the care they receive.

#### 4.1 | The challenge of fitting into institutional care

Some care homes operated in a manner that was task-orientated and rule-driven (Bangerter et al., 2016; Cho et al., 2017; Dybvik et al., 2014; Nygaard et al., 2020; Palacios-Ceña et al., 2013; Wang et al., 2016), prioritising routine tasks or organisational activities over residents (Donnelly & MacEntee, 2016; Ludlow et al., 2021; Palacios-Ceña et al., 2013). This left residents' feeling constrained by the day-to-day routine and care home structures (Dybvik et al., 2014) and treated as "random care recipients" (Wang et al., 2016, p. 39). One resident suggested:

"There are lists for everything here: unable to walk list, unable to eat list, wheelchair users list...", "... You urinate on your turn, not when you feel like it..." (Palacios-Ceña et al., 2013).

Although some residents were grateful for their care needs being met by nurses and care home professionals (Dybvik et al., 2014; Minney & Ranzijn, 2016) many felt they could be more empowered to care for themselves. Or, at very least, to have choice over how and when their care was received (Chuang et al., 2015; Cook et al., 2015; Harrison & Frampton, 2017; Walker & Paliadelis, 2016) rather than just fitting into the care home's routine (Donnelly & MacEntee, 2016; Dybvik et al., 2014). This resident shared:

"I get up, helped to get ready, have breakfast and then I would be taken to the day lounge. Then lunch, then tea and then back to bed. That is how it is, every day!" (Cook et al., 2015).

#### 4.2 | The passing of time

Residents voiced feelings of boredom (Mjørud et al., 2017) and loneliness (Walker & Paliadelis, 2016) due to a lack of activities (Cho et al., 2017; Cook et al., 2015; Drageset et al., 2017; Dybvik et al., 2014; Mjørud et al., 2017; Nygaard et al., 2020). They also noted a lack of any meaningful social contact (Bangerter et al., 2016; Chuang et al., 2015; Ludlow et al., 2021; Minney & Ranzijn, 2016). To pass the time (Cook et al., 2015) and fill the day, residents often sought to form relationships with care home professionals and nursing staff, expressed by these residents:

"I chat to whoever is passing by in the staff...you are just looking at passing the time I suppose" (Cook et al., 2015). As otherwise, they became "very lonely... just keep watching the ceiling. And, I really like to have companionship from the nursing staff" (Chuang et al., 2015).

The topic of death featured amongst some residents' thoughts in relation to the passing of time (Chuang et al., 2015; Harrison &

Frampton, 2017; Walker & Paliadelis, 2016) as displayed by this resident quote:

"I have told my daughter (about my death) and wanted to say a nice goodbye" (Chuang et al., 2015).

Nevertheless, for many more, living their lives in the best way they could was more prominent in their minds (Cook et al., 2015; Minney & Ranzijn, 2016; Mjørud et al., 2017; Nygaard et al., 2020).

#### 4.3 | Holding onto a sense of self

To be able to hold onto a sense of self, agency and autonomy, and being recognised and valued were critical to residents (Cho et al., 2017; Chuang et al., 2015; Cook et al., 2015; Donnelly & MacEntee, 2016; Walker & Paliadelis, 2016; Wang et al., 2016). Residents often felt they lacked control and choice (Harrison & Frampton, 2017) over their care provision, their activities, and their overall day-to-day lives (Chuang et al., 2015; Cook et al., 2015; Palacios-Ceña et al., 2013; Walker & Paliadelis, 2016). A resident quote within Walker and Paliadelis (2016) illustrates this:

"Well, I'd like to (have) freedom to get around and get around the back yard and little things like that but can't bear it when you're locked, you're locked in, you're just in all day in the room" (Walker & Paliadelis, 2016).

Some residents felt they were not listened to, and often decisions were made without including them, leading to a sense of hopelessness and helplessness (Donnelly & MacEntee, 2016), with some seeing little purpose for living (Walker & Paliadelis, 2016), captured by this resident:

"I don't have any hope or thoughts. I just wonder whether it's better to die now or later" (Cho et al., 2017).

#### 4.4 | A desire to feel at home

Residents often found the transition into care homes difficult. Although most wanted to feel at home in their new residence (Cho et al., 2017; Cook et al., 2015; Mjørud et al., 2017; Palacios-Ceña et al., 2013; Walker & Paliadelis, 2016). Some were unable to adjust successfully to the transition. Whereas others adapted (sometimes reluctantly) as shown by these residents:

"...as long as you are not home, it cannot be better than this... I live here, I will be content here" (Mjørud et al., 2017);



"I knew I had to get used to it because I knew I'd be here till they cart me out" (Walker & Paliadelis, 2016).

Although residents reflected on the homes and communities they had lost, they also acknowledged that moving into a care home could bring with it safety and security, which they greatly valued (Chuang et al., 2015; Dybvik et al., 2014; Minney & Ranzijn, 2016; Mjørud et al., 2017; Nygaard et al., 2020; Palacios-Ceña et al., 2013). For example, one resident said:

"I know I'm being looked after, and I don't have to worry about anything. I didn't always feel safe before" (Minney & Ranzijn, 2016).

#### 4.5 | Key concept one: Creating a culture of purposeful living and caring

The first key concept, 'creating a culture of purposeful living and caring' underlines the importance of creating environments and cultures in which residents can live, as much as is possible, in the way they want. In this key concept, culture represents the residents' subjective lived experiences of care (Rytterström et al., 2013), rather than organisational or outcome-measured definitions of cultures of care (Greenhough et al., 2022).

The impact of institutional rules and regulations and low staffing levels led some residents to feeling they were not living purposefully. This is emphasised by Cook et al. (2015, p.1594) who highlight residents' desire to "live with care rather than exist in care". Although some residents managed to find purpose:

"Oh, I can control my own life...and that is a big thing. You know I wouldn't like to keep having to ask the staff to take me here or to do this for me or do that. When you can do it yourself, it is much better. It makes it your life more pleasant" (Cook et al., 2015).

When staffing levels were low, some residents reported that they felt restricted, confined, and unable to do the things they wanted, shared by this resident:

"At times, it seems they move us like furniture...they're all rushing, non-stop...you must ask for permission for everything" (Palacios-Ceña et al., 2013).

Meaningful activities were important to residents (Bangerter et al., 2016; Cho et al., 2017; Cook et al., 2015; Drageset et al., 2017; Dybvik et al., 2014; Mjørud et al., 2017; Nygaard et al., 2020) not only to pass the time but also as it made them feel part of the community in which they resided. One resident said:

"When I hear and see others laugh and enjoy [themselves], I desperately want to join them" (Cho et al., 2017).

Some residents relished the opportunity to contribute to the day-to-day activities of the home, as it gave them purpose. When offered the chance to support the nurses and other care home professionals, one resident recalled:

"Yesterday we were short of staff, and I was in the kitchen and I was a carer, you know, I did everything. They all said, 'oh, you did work so hard!' I felt needed; do you know what I mean? It felt like the old times and that was really good" (Minney & Ranzijn, 2016).

Residents were very aware that ageing had brought with it challenges that restricted their ability to do what they previously had (Cho et al., 2017; Donnelly & MacEntee, 2016), with one resident expressing:

"What can I do? Nothing...I am good for nothing" (Mjørud et al., 2017).

However, without the creation of a culture that encouraged and empowered residents to find purpose and offer meaningful activity and relationships, many were just left thinking about when their end of life would arrive. As captured by this resident's comment:

"I am just an old man living in a nursing home. We are the sunset now, wasting resources" (Wang et al., 2016).

#### 4.6 | Key concept two: Forming and maintaining meaningful and empowering relationships

The second key concept, 'forming and maintaining meaningful and empowering relationships' recognises the importance of relationships developing between residents and care home professionals, but also amongst residents themselves. Residents also valued their connections with people outside of the care home community (Dybvik et al., 2014), especially family and friends (Harrison & Frampton, 2017; Mjørud et al., 2017; Walker & Paliadelis, 2016; Wang et al., 2016). One resident described this as:

"Being together with old friends and family...makes life meaningful" (Drageset et al., 2017).

Forming and maintaining these relationships helped residents, especially those with cognitive impairment, hang onto a sense of self (agency and autonomy) and aided them to feel at home rather than feel that they lived in an institution. This link between a residents' sense of self and the relationships with those around

them is summed up particularly well by Nygaard et al. (2020, p.5) first theme “myself and my relationships with fellow residents”. This theme highlighted the frustration of living in a care home with many others but not really knowing them, expressed by this resident:

“We’re a weird bunch getting together here, but we’re not together...that’s what makes us so different” (Nygaard et al., 2020).

Relationships were valued as they offered a sense of belonging, and gave meaning and purpose to their new lives in their care homes with one resident suggesting:

“It is necessary to have friends here. (I) feel more cheerful, much happier and valued” (Chuang et al., 2015).

Relationships, as well as being meaningful, could also be empowering. This was especially when they were with nurses and other care home professionals who sought to give purpose to their residents’ lives (Bangerter et al., 2016; Minney & Ranzijn, 2016) and enable them to make decisions about their own care. One resident stated:

“They ask me what time I want to get up and when I want my shower” (Harrison & Frampton, 2017).

Where these mutually respectful and empowering relationships were lacking residents reported that they felt the invalidated and infantilised, as shared by this resident quote:

“They think we’re all retarded and about to wet our pants at any moment and not having a brain in our heads... They talk to you like you are a child” (Donnelly & MacEntee, 2016).

Residents recognised the work pressure nurses and other care home professionals were under and just how busy they were. For example, a resident stated:

“They don’t spend much time with you because they’re busy, busy, busy” (Ludlow et al., 2021).

Although they were sometimes unsure what their carers did that took up so much of their time, as shared by this resident:

“They are quite busy, but I don’t know what they are busy with?” (Wang et al., 2016).

Nevertheless, those who were able to form relationships with nurses and other care home professionals valued those friendships as highlighted by this resident:

“They are friends of ours and they treat us like that” (Walker & Paliadelis, 2016).

## 4.7 | Conceptual framework

The conceptual framework of understanding collectively represents and synthesises the interrelationships between the four conceptual categories (the challenge of fitting into institutional care, the passing of time, holding onto a sense of self and a desire to feel at home) and the reciprocal translation (two key concepts: creating a culture of purposeful living and caring and forming and maintaining meaningful & empowering relationships). The framework captures a conceptual understanding of what personally matters to residents in terms of their care and identifies the importance of maintaining a sense of self and a sense of feeling at home. This is particularly important for residents during the transition into care, where they are often faced with the challenges of adapting to the institutional rules and regulations that a care home setting can bring.

The framework also highlights that time is important, both in temporal terms of *life lived and being lived*, but also as a resource provided to residents. However, time is often kept for institutional tasks rather than meaningful activities and relational interactions. At the centre of the framework is the resident seeking empowerment from those around them to achieve what personally matters to them. If personalised care practices are to exist and thrive in care homes residents will need to be accessed through a person-centred care approach (the conceptual doorway of framework). This is the only way to understand what matters to them.

## 5 | DISCUSSION

Our meta-ethnography has translated and synthesised 15 (resident-focused) international qualitative studies (Norway, Australia, US, Canada, China, South Korea, Spain, Taiwan, and UK) into a new understanding of what personally matters to residents in terms of the care they receive. Four conceptual categories and two key concepts were identified through a process of qualitative data translation and synthesis. These conceptual components were combined into a LOA synthesis presented as a conceptual framework of what personally matters to residents in terms of the care residents receive. Although some ‘what matters to residents’ themes (choice, relationships and meaningful activity) remain similar over the last decade (Baxter et al., 2021; Bradshaw et al., 2012; McCormack et al., 2012; Popham & Orrell, 2012), the framework developed from our meta-ethnography highlights the conceptual factors beneath these key themes (sense of self and time, and home versus institute). Our findings suggest that if these underpinning conceptual factors can be addressed through a person-centred (*doing with*) and relational approach, then purposeful and meaningful personalised care environments can exist.

Like Gadd and Cronin's (2018) National Framework of person-centred planning, our framework also includes the terms personalised and person-centred. Gadd and Cronin (2018, p.13) describe personalised care as "what is important for the person" and person-centred care as "what is important to the person". Our conceptual framework (Figure 2) applies the same principles. By using a person-centred approach to understand the resident's needs and the challenges they face adjusting to institutional care, the nurse or care professional can appreciate what personally matters to the resident rather than focusing on what might be important for them. In doing so, this provides an inclusive care culture that moves the focus of attention away from the typical physical and cognitive decline narrative towards "fostering an atmosphere of everydayness" (Kelly et al., 2019, p.554). This *person-centred approach* towards *personalised care* gives agency to residents to lead on day-to-day decision-making, and reminds nurses and care home professionals "to facilitate not fix" (Kime et al., 2022, p.8).

The findings suggest that maintaining a sense of agency and autonomy are important factors for care home residents as it preserves a sense of belonging and meaning to residents' lives. One way to do this is to provide organisational structures that support empowering and meaningful relationships to be formed and maintained between care home professionals and their residents (Fazio et al., 2018), and indeed, the residents themselves. These are "healthful relationships" (McCormack et al., 2013, p. 193) that value and respect each resident's individuality and empowers them to maintain their sense of self and personhood through relationships with others (Kitwood, 1997; McCormack et al., 2012).

Residents were very clear that having and experiencing a purpose to life was also important to them. This not only included purposeful care home practices and activities, which are known to foster engagement and improve wellbeing (Owen et al., 2021), but also the ability to purposefully age. Residents wanted to be seen as an asset within the care home and not as a burden (Milken Institute, 2016). The feeling of being a burden often begins at the transition from home into residential care settings, which for some brought with it significantly increased levels of dependency on others (Donnelly & MacEntee, 2016; Ludlow et al., 2021).

## 5.1 | Strengths and limitations

The ethical and methodological questions of reusing other researchers' data and the importance of secondary reviewers keeping primary source quotes in context (Campbell et al., 2011) needs to be acknowledged as a potential limitation. However, this has been mitigated to some degree by using eMERGe Reporting Guidance (France et al., 2019a) and by all 15 studies including some form of ethical consideration or approval (CASP, 2021).

The meta-ethnography and its concluding framework of understanding offers an international perspective of what matters

to residents by representing voices across diverse but comparable care home settings (nursing, residential and long-term care facilities) and populations. This is both a strength, as it suggests reciprocal findings across an international data set, but also a limitation in that there will be differing care priorities, practices, and policies across international settings. This requires careful consideration of the context in which primary source quotes were used.

Many of the selected studies in our meta-ethnography cited dementia or cognitive impairment as an exclusion to participation. This is a limitation of the body of work in this area as many residents living in care homes across the world will have a cognitive impairment or dementia diagnosis, and researchers need to find ways to include their perspectives of the care they receive. Finally, although the juxtaposition of the terms personalised and person-centred care is addressed in our meta-ethnography, the terms interchangeable use across policy, practice, and research makes comparison more challenging.

## 5.2 | Implications for policy, practice and research

The findings of our meta-ethnography are of international relevance and concern. It is therefore paramount that these important areas of social and health care policy are addressed through international practice and research collaborations.

When considering future policy, practice and research, the term personalised care is perhaps problematic as it suggests a top-down ideology where experts collectively meet the needs of passive recipients (Mladenov et al., 2015). Person-centred care may be a more appropriate term because it means decisions are made by the resident and not for them. However, in the UK it has become a ubiquitous term that has perhaps lost its origin of meaning (Godfrey et al., 2018). To facilitate cultures of care that encourage, rather than discourage, resident agency, autonomy and centrality (person-centredness) we need to provide nurses and social care professionals with training and development opportunities that focus on the importance of resident choice, control, and consent, rather than relying on personalised rhetoric within policy documents and practice guidelines.

The findings of this review highlight a scope for further research on the challenges residents face when adjusting to moving into a long-term care home setting. This could include exploratory studies on ways to maintain older peoples' personal agency, autonomy, and identity during their transition into long-term care settings and institutional care. To do this, residents, families, nurses and social care workforce voices will need to be central to future research development, not only as participants but also as research collaborators and partners. Finally, it is a priority that residents living with a cognitive impairment or dementia are supported to participate in research, as too often their voices are silenced by ethical challenges and exclusion criteria.

## 6 | CONCLUSION

Our meta-ethnography has drawn on the themes and interpretations of 15 international studies to offer a new resident-focused understanding of personalised care in care homes by capturing and amplifying the voices of the research participants. In doing so, it has produced a conceptual framework that is accessed through a person-centred approach and guided by the centrality of the care home resident.

The voices shared highlight the importance of moving from an institutionally personalised position of *doing for* residents to a person-centred position of *doing with* residents by providing purposeful cultures of care and forming and maintaining of meaningful and empowering relationships. There are, of course, times when *doing for* care is required and therefore personally valued by the residents. However, the *doing with* care moments are the moments where dependency is diminished and empowerment is nurtured.

The number of people living in care homes across the UK, Europe, and worldwide is significant, and the challenges faced by care home residents transitioning into long-term care home settings are similar. Therefore, the findings of our meta-ethnography go some way towards a growing call to develop collaborative national and international research, practice, and policy that will impact positively on the delivery of person-centred care in care homes. Especially, if it is guided by care home residents themselves.

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### CONFLICT OF INTEREST STATEMENT

The authors have no conflicts of interest to declare.

### DATA AVAILABILITY STATEMENT

The data that supports the findings of this study are available in the supplementary material of this article.

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## SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.