



University of
Salford
MANCHESTER

A critical realist evaluation of advance care planning in care homes

Spacey, A, Scammell, J, Board, M and Porter, S

<http://dx.doi.org/10.1111/jan.14822>

Title	A critical realist evaluation of advance care planning in care homes
Authors	Spacey, A, Scammell, J, Board, M and Porter, S
Publication title	Journal of Advanced Nursing
Publisher	Wiley
Type	Article
USIR URL	This version is available at: http://usir.salford.ac.uk/id/eprint/59807/
Published Date	2021

USIR is a digital collection of the research output of the University of Salford. Where copyright permits, full text material held in the repository is made freely available online and can be read, downloaded and copied for non-commercial private study or research purposes. Please check the manuscript for any further copyright restrictions.

For more information, including our policy and submission procedure, please contact the Repository Team at: library-research@salford.ac.uk.

A critical realist evaluation of advance care planning in care homes

Adam Spacey¹  | Janet Scammell²  | Michele Board² | Sam Porter³ 

¹School of Health and Society, University of Salford, Salford, UK

²Faculty of Health and Social Sciences, Bournemouth University, Bournemouth, UK

³Department of Social Sciences and Social Work, Bournemouth University, Bournemouth, UK

Correspondence

Adam Spacey, School of Health and Society, University of Salford, Salford, UK.
Email: a.spacey@salford.ac.uk

Funding information

This research received no specific grant from any funding agency in the public, commercial, or not-for-profit sectors.

Abstract

Aims: To evaluate care planning in advance of end-of-life care in care homes.

Design: A qualitative study.

Methods: Qualitative data were collected from January 2018–July 2019 (using focus groups and semi-structured interviews) from three care homes in the South West of England. The data were analysed using thematic analysis followed by Critical Realist Evaluation.

Results: Participants comprised of registered nurses ($N = 4$), care assistants ($N = 8$), bereaved relatives ($N = 7$), and domiciliary staff ($N = 3$). Although the importance of advance care planning was well recognized, the emotional labour of frequently engaging in discussions about death and dying was highlighted as a problem by some care home staff. It was evident that in some cases care home staff's unmet emotional needs led them to rushing and avoiding discussions about death and dying with residents and relatives. A sparsity of mechanisms to support care home staff's emotional needs was noted across all three care homes. Furthermore, a lack of training and knowledge appeared to inhibit care home staff's ability to engage in meaningful care planning conversations with specific groups of residents such as those living with dementia. The lack of training was principally evident amongst non-registered care home staff and those with non-formal caring roles such as housekeeping.

Conclusion: There is a need for more focused education to support registered and non-registered care home staff to effectively engage in sensitive discussions about death and dying with residents. Furthermore, greater emotional support is necessary to help build workforce resilience and sustain change.

Impact: Knowledge generated from this study can be used to inform the design and development of future advance care planning interventions capable of supporting the delivery of high-quality end-of-life care in care homes.

KEYWORDS

death and dying, long-term care, nursing home care, palliative care

This is an open access article under the terms of the Creative Commons Attribution License, which permits use, distribution and reproduction in any medium, provided the original work is properly cited.

© 2021 The Authors. *Journal of Advanced Nursing* published by John Wiley & Sons Ltd.

1 | INTRODUCTION

End of Life Care (EoLC) in care homes is becoming the focus of growing attention due to the rapidly ageing population across developed countries (United Nations [UN], 2017). In Europe, care homes are increasingly becoming the most common places of death (Andreasen et al., 2019), and in the UK it is predicted that care homes will be the most common place of death by 2040 (Bone et al., 2018). In the UK, the generic term 'care home' describes both residential and nursing homes. Both of these types provide food and board, 24-h care cover and assistance where required with activities of daily living. In addition, nursing homes provide care by registered nurses (Laing & Buisson, 2016). Both provide EoLC.

Collectively, the care home sector in the UK provides care for approximately 418,000 people which represents 4% of the population aged over 65 and 15% aged over 85 (Laing & Buisson, 2016). Given age is synonymous with progressive chronic illnesses (World Health Organisation [WHO], 2017), more people are now living in care homes with multiple chronic conditions (multiple comorbidities), such as Dementia and frailty (Kingston et al. 2018).

It is therefore important that care homes staff are able to provide quality, person-centred care for residents approaching the end of their life often with multiple chronic conditions (Aasmul et al., 2018). Although the definition of end of life (EoL) differs between countries, is generally considered that people are probably to die in 12 months (National Health Service [NHS], 2018). Care provided during this period is termed EoLC which comforts and supports people who are dying from a progressive life-limiting condition (Fisher et al., 2000). Furthermore, EoLC should be person-centred which involves considering the persons wishes, values, beliefs and family circumstances; and incorporating these factors into their care (Fisher et al., 2000; Kitson et al., 2013). Advance care planning is the most common tool used by care home staff to support person centred EoLC (Spacey et al., 2020).

Although advance care planning practices can vary depending on the cultural and legal contexts of different countries (Sharp et al., 2013), efforts to standardize the definition have been made (Sudore et al., 2016). An international multidisciplinary panel described advance care planning as a process that supports individuals to share their personal values, life goals, and preferences about future care (Rietjens et al. 2017; Sudore et al., 2016). The advance planning process usually consists of a discussion between care home staff, the resident and/or their family, which is documented in an advance care plan (National Institute for Health & Care Excellence [NICE], 2019). Regardless of country, it has been well established that advance care planning can improve care quality, reduce unnecessary admission to hospitals, and decrease stress and anxiety for both residents and their family members (Aasmul et al., 2018).

Thus, the care home staff delivering EoLC need to plan, gather and record information about a person's wishes and preferences and take them into account to provide the best care possible for that person (Cloninger, 2011). Despite the importance of advance care planning in care homes, research has highlighted a lack of insight

from the care home staff engaging in advance care planning, as well as the perceptions of family members (Spacey et al., 2018).

1.1 | Background

Given the increasing numbers of residents dying in care homes, and the complexities associated with advance care planning a plethora of interventions have been designed to support care home staff to engage in advance care planning discussions with residents and their family members (Braun & Zir, 2005; Cronfalk et al., 2015; Mayrhofer et al., 2016; McGlade et al., 2017; O'Sullivan et al., 2016; Temkin-Greener et al., 2017). The main focus of these interventions tends to be on educating staff on the importance of advance care planning, how to approach such conversations with residents and the legal and cultural factors associated with care planning (Sharp et al., 2013). For example, some residents may not want to discuss death and dying due to cultural or religious beliefs. Education also informs care home staff of The Mental Capacity Act (2005), and in cases where a resident lacks mental capacity, a legally appointed decision maker can engage in the care planning process on their behalf.

Both registered and non-registered care home staff are involved in advance care planning and are responsible for delivering patient-centred care for people at the end of their life (Leaman 2011). Despite this, existing studies have not explored to perceptions of both registered and non-registered care home staff engaging in care planning (Spacey et al., 2020). The UK care home workforce is made up of non-registered care assistants (76%) and registered nursing staff (12%); the remaining workforce is made up of ancillary staff such as housekeeping and administrative staff (Griffiths et al., 2019).

Despite these complexities, current research tends to be outcome rather than process focused with the number of advance care plans in place for residents receiving EoLC being the most commonly reported marker of the quality care (Garden et al., 2016; Kinley et al., 2014). A recent systematic literature review evaluating advanced care planning interventions found that these outcomes were often short lived and that the numbers of advance care plans dropped post-intervention suggesting limited sustainability (Spacey et al., 2020). The reasons for this are currently unclear due to a sparsity of research exploring the underlying processes behind advance care planning in care homes. Specifically, current evidence about the rationale behind intervention design, the effect of context, and the response of stakeholders is sparse. This means that the impact of these factors on outcomes has thus far not been adequately established.

2 | THE STUDY

2.1 | Aims

This study aims to evaluate care planning in advance of end-of-life care in care homes. The following research questions were set to achieve this aim:

- What mechanisms currently exist to support care home staff to effectively engage in advance care planning? (intervention mechanisms)
- Can the context of care homes influence advance care planning? (contextual mechanisms)
- How do stakeholders tend to respond to advance care planning? (human agency)

2.2 | Design

This study reports on the results developed over the course of a two-phased study that adopted a Critical Realist design (Porter, 2015), which assumes that the outcomes of interventions result from the interaction of a plurality of causal mechanisms. Mechanisms are embedded in the intervention itself (intervention mechanisms); in the social and organizational context (contextual mechanisms); all of which are filtered through individuals' interpretations and responses (Human agency; Porter, 2015). Thus, each of the above causal categories will be used to explore advance care planning in care homes. Table 1 details each of the causal categories.

Qualitative data was collected from January 2018–July 2019 using serial semi-structured interviews and focus groups to explore advance care planning in three care homes in the South West of England. Participants included bereaved relatives ($N = 7$), registered nurses (including managers; $N = 4$), care assistants ($N = 8$) and domiciliary/administrative staff ($N = 3$) who were all interviewed twice. All participants had been involved in advance care planning. The qualitative data were transcribed verbatim, analysed and results were reported in accordance with the Consolidated criteria for reporting Qualitative Research guidelines (Tong et al., 2007).

2.3 | Setting

The Care Quality Commission's (CQC) electronic database was used to search for care homes in one county in the South West of England to include both residential and nursing homes. The CQC is an independent regulator of health and social care services in England. Purposive sampling was also used for the selection of data collection sites (Tongco, 2007) to ensure variation in the care homes settings.

Moreover, the local Care Commissioning Group (which are government run organizations responsible for commissioning most hospital and community services in England) provided advice throughout the process which was used to develop the following purposive sampling variables and eligibility criteria (Table 2):

Using the purposive sampling method and the eligibility criteria, five care homes were selected and approached. The first three care homes that agreed to participate that met the eligibility criteria were invited to take part in the study. Three variations of care homes were chosen because they represent the largest proportion of care homes types in the UK (Competition & Markets Authority [CMA], 2017; Laing & Buisson, 2016; see Table 3).

2.4 | Sample/Participants

The selection of participants was informed by two systematic literature reviews carried out by the authors (Spacey et al., 2018, 2020), which revealed that few studies reported on experiences of advance care planning from the perspectives of bereaved relatives, particularly those from a residential setting. Additionally, whilst current literature explored the experiences of registered care home staff, the perspectives on non-registered care home staff, especially those with non-formal caring roles were often overlooked (Spacey et al., 2020). After discussion with the participating care homes and the ethics committee, it was deemed inappropriate to include residents who were receiving EoLC in this study. Specifically, the researcher would not be aware of residents' level of knowledge as to whether they knew they were receiving EoLC, so it was deemed insensitive and unethical to ask them about EoLC. However, the inclusion of bereaved relatives added a broader service user's perspective. All included participants and their allocated pseudonyms are detailed in Table 4.

To aid staff recruitment, researchers attended staff meetings to inform the staff about the study and hand out invitation letters to potential participants. This enabled those who expressed an interest to contact the researcher independently of the care home manager. Bereaved relatives were contacted through managers using an invitation letter which included the researcher's contact details. When the potential participants expressed an interest in taking part in the study, they were provided with participant

TABLE 1 Critical Realist terminology and definitions

Terminology	Definition
Intervention mechanisms	The mechanisms contained in interventions which are designed to change the behaviour of those at whom they are targeted
Contextual mechanisms	The resources and restrictions embedded in the social and organizational context may inhibit or promote the effectiveness of intervention mechanisms
Human agency	People's experiences, interpretations and responses to the intervention and contextual mechanisms
Outcome	The changes in behaviour that result from how people respond to the intervention and contextual mechanisms

TABLE 2 Overview of sampling variables and eligibility criteria

Purposive sampling variables	Ownership of care home—Single owner/Corporate owner/Local authority owned Size of home—Small/Medium/Large Setting—Urban/Rural Care home registration status—Nursing/Residential/Dual (both residential and nursing)
Eligibility criteria	The care homes (both residential and nursing) must provide end of life care for older residents. Included care homes must be located in the South West of England area for pragmatic reasons as this is the local area for the research project and team. Included care homes must be commercially owned, as the private sector significantly represents the largest care home sector in the UK.

Care home	Ownership	Size	Setting	Registration status
Care home one (C1)	Single owner private sector care home	32 bed home	Urban	Residential care
Care home two (C2)	Corporately (chain) owned private	42 bed home	Urban	Joint nursing and residential care
Care home three (C3)	Single owner private sector care home	75 bed home	Urban	Nursing care

TABLE 3 Details of the included care homes

Care homes	Participants		
	Care home managers	*Registered and **non-registered care home staff	Bereaved relatives (BR)
C1: Care home one	Manager C1 (10 years' experience and registered nurse, RN)	Care assistant 1 C1 (5 years' experience) Care assistant 2 C1 (10 years' experience) Care assistant 3 C1 (3 years' experience)	BR1 C1 BR2 C1 BR3 C1
C2: Care home two	Manager C2 (15 years' experience and registered nurse, RN)	Housekeeping C2 (1-year experience) Care assistant 1 C2 (29 years' experience) Care assistant 2 C2 (14 years' experience)	BR4 C2 BR5 C2
C3: Care home three	Manager C3 (6 years' experience and registered nurse, RN)	Registered nurse 1 C3 (19 years' experience) Care assistant 1 C3 (28 years' experience) Care assistant 2 C3 (2 years' experience) Care assistant 3 C3 (2 years' experience) Administrator C3 (5 years' experience) Housekeeping C3 (5 years' experience)	BR6 C3 BR7 C3

TABLE 4 Participant pseudonyms and details

information sheets, and a consent form. No participants refused to participate.

2.5 | Data collection

There were two phases of data collection meaning participants were interviewed twice. The questions used in phase one for the focus groups

and semi-structured interviews were developed from two systematic reviews of the literature (Spacey et al., 2018, 2020). Phase two involved presenting the initial findings to the participants (from phase one) using focus groups and semi-structured interviews. Murray et al. (2009) found that the use of repeating or serial interviews helped to uncover the complexities of individual situations by allowing narratives to develop.

Both sets of focus groups with registered nurses and care assistants lasted 1 h and were conducted by two researchers, one acting

as facilitator, the other as moderator. The semi-structured interviews (with bereaved relatives and care home managers) lasted up to 45 min. All the researchers participated in data collection, and had experience of qualitative interviewing and had no prior relationship with the participants.

Staff interviews and focus groups were conducted in private rooms in the participating care homes, and the interviews with bereaved relatives were carried out in their own homes or the University. All interviews were audio-recorded, and the moderator took notes during the focus groups. The participants were informed that we were researchers conducting a study exploring EoLC in care homes.

2.6 | Ethical considerations

Ethics approval was granted on the 15/01/2018, by the Health Research Authority, a UK government arm of the National Health Service providing governance of health research (Regional Ethics Committee reference 27/LO/1828).

2.7 | Data analysis

Analysis was carried out at the same time as data collection for each phase, and was discussed during fortnightly meetings of the research team; this helped determine sample size and data saturation. Throughout the process, analysis was triangulated by the four members of the team. A different mode of analysis was used for each of the two phases of focus groups and semi-structured interviews. The primary purpose of the first phase was to attain descriptive data about the use of advance care plans in care homes. The data gathered were thematically analysed (Braun & Clarke, 2006) by coding to identify recurring patterns. These patterns were arranged into themes and subthemes that augmented, refuted or refined the theoretical insights about intervention mechanisms, contextual mechanisms, human agency, and outcomes that had been developed previously from our critical realist review of the literature (Spacey et al., 2020) to establish what works, for whom and in what circumstances. The primary purpose of the second round was to present these theories to participants and discuss their validity and implications. Credibility was enhanced by ongoing interaction with the data during collection as well as during analysis.

2.8 | Rigour

A variety of strategies were used to ensure rigour (Lincoln & Guba, 1985), for example, the initial analysis by the lead researcher (AS) was triangulated by the other members of the research team (JS, MB, SP), to confirm key themes and sub-themes. Furthermore, a reflexive record during data collection and analysis was kept, and fortnightly meetings to discuss and record the decisions made during

analysis were held. These strategies helped to confirm the credibility of the emerging findings. Lastly, the second round of interviewing that involved a discussion with participants about the adequacy of the researchers' theories helped improve credibility and validity.

3 | FINDINGS

Findings are organized according to the critical realist evaluation categories of intervention mechanisms, contextual mechanisms and human agency.

3.1 | Intervention mechanisms

This section examines the generative mechanisms embedded in interventions that were hypothesized to promote behaviour conducive to supporting more effective advance care planning. These consisted predominantly of educational initiatives.

3.1.1 | Education to support advance care planning

Education mechanisms were identified during both phases of this study and recognized as being key to providing care home staff with the skills and knowledge to effectively and sustainably carry out advance care planning discussions. Analysis suggested that shadowing (where colleagues would observe each other's practice) was used by experienced care home staff (5 or more years' experience) to train less experienced staff to engage in advance care planning discussions with residents and relatives. Shadowing was used by both registered nurses and non-registered care assistants, enabling them to learn from each other how to approach and sensitively build up to discussions about death and dying.

Care assistant 2 C1: They can observe how I start the conversation and build up to some of the sensitive topics...I think this has to be experienced...seeing how others do it.

Registered nurse 1 C3: ...those who are new with less hands-on experience watch how I style certain questions...I talk them through it all afterwards as well...

Analysis of the data across all three care homes in this study suggested that shadowing was the most common education mechanism used to improve practice related to advance care planning and person-centred care. The data implied that care assistants found methods such as shadowing to be effective due to the 'practical' nature of their job rather than having more formal education.

Care assistant 1 C1: It's very practical you just have to get it done we learn from watching each other on the job that's how I learnt anyway... when we get new staff, we put them with the older staff so they can pick things up and learn.

However, shadowing was not the only educational method used to support advance care planning. Analysis of the transcripts from care home three uncovered a range of education mechanisms used by the care home staff from workshops to video sessions to accompany shadowing as part of the Gold Standard Framework for care homes (GSFCH) programme. The GSFCH is a framework used to support the early identification of residents approaching the end of their life, and to help them plan ahead (The Gold Standards Framework [GSF], 2018).

Registered nurse 1 C3: Training is provided through workshops and paperwork like the portfolio that come with the framework. We have video sessions that we watch throughout the year too...

Despite only one care home using these additional education strategies, several benefits were evident which appeared to be unique to the workshops and videos. Specifically, educational workshops tended to include more diverse groups of care home staff compared with shadowing. For example, it was evident that staff with non-formal caring roles such as housekeeping engaged in workshops and videos on advance care planning. This is an important finding as bereaved relatives valued staff with non-formal caring roles being part of their loved one's care in terms of advance care planning. For example, bereaved relatives expressed developing good relationships with housekeeping staff helped them feel more comfortable and able to share information with them pertaining to their loved one's care.

BR5 C2: I also dealt a lot with cleaning staff when they would come in the room, they made conversation with us, my aunt took a liking to one of them....

The section has highlighted some of the different education mechanisms employed in care homes to support staff engagement in advance care planning discussions. Data collected from bereaved relatives suggests that there may be some benefits to including a more diverse range of care home staff in advance care planning training.

3.2 | Contextual mechanisms

This section will explore the resources and restrictions embedded in the social and organizational context which were hypothesized as either promoting or inhibiting the effectiveness of advance care planning. Two significant contextual mechanisms were identified: financial variability between care homes and the diversity of residential populations.

3.2.1 | Financial variability in the care home sector

Analysis of the initial interview transcripts identified financial and organizational barriers to the implementation of education and

training to support staff to engage in advance care planning. It was apparent that the type and size of care home influenced their financial and organizational ability to deliver and sustain intervention mechanisms. Specifically, care home one was a small residential home with 32 beds, which delivered EoLC a few times a year, while care home three was a 75-bed nursing home where EoLC was delivered far more frequently.

Care assistant 2 C1: We do not deliver much end of life care here, so we only have a few deaths a year. Usually quite a few in a short amount of time, then you'll go through a period where lots die. It's always Christmas before or after. So, when a death comes it can be hard hitting, we're not as used to it as some other places may be.

It was acknowledged that the GSFCH provided useful education and training to help a more diverse range of care home staff engage in advance care planning. However, managers from care homes one and two spoke about the time commitments with setting up such training interventions, compounded by the implementation costs which were not viable in their smaller homes.

Manager C1: Lots of homes are signed up for the Gold Standards Framework then you have to update it and keep paying... we are a residential small home so would rather not be paying for training that may not work for us and that may be phased out soon. We cannot afford to waste money like that.

This data suggests that financial and organizational contexts are preventing these homes from benefiting from many of the supportive mechanisms that come with the GSFCH, that care home three was able to use. The manager from care home three highlighted that they had more financial freedom compared with other homes which allowed for flexibility in terms of training and education. However, the manager from care home three also highlighted that providing EoLC is an important priority that should not come down to financial resources.

Manager C3: We've got that flexibility and I just wish other homes had that. There is a financial thing in that. But you can't put a price on end of life care; the memories are everything to a loved one, if you don't get it right you've had it.

3.2.2 | The diverse resident population

During phase two of the study care home staff expanded on the diverse resident population, highlighting some of their perceptions in regard to caring for residents living with dementia. Our findings indicate that some care home staff assumed residents with dementia would get too upset or would not understand if they talked about

death and dying. Therefore, to avoid upset and confusion, some care home staff would avoid sensitive discussions with residents living with dementia and discuss with the next of kin.

Care assistant 1 C2: ...for residents who have dementia we go to their families directly because it can be very upsetting, and it can confuse the resident even more if we start asking too much questions. It's about supporting them to enjoy the time they have left.

The perception that talking about death and dying would confuse or upset residents living with the dementia was not only apparent in the quotes from care assistants. Managers spoke about the increasingly demanding and complex EoLC needs of residents. The manager from care home one spoke about how residents requiring EoLC frequently have multiple conditions such as frailty and dementia. The complex and 'high needs' of residents living with dementia as well as their mental capacity was used to justify this behaviour.

Manager C1: Over the past few months a lot of our residents have become high needs and we haven't got many that have [mental] capacity. So mostly it's about discussing it with the next of kin and not the resident. You've got to think what is right for that person, so if they don't understand what you're talking about, why you going to talk to them about dying that's not nice.

These findings imply that some care home staff's perceptions prevented residents with dementia from being involved and contributing to their own care. Rather than attempt to engage or assume capacity, these staff assumed a lack of capacity and went straight to the family, excluding the resident living with dementia. Similar findings in regard to discussing death and dying as part of advance care planning were evident when analysing the bereaved relatives' experiences. One bereaved relative explained that the care home staff went directly to her as the next of kin to ask about her husband's preferences who was living with dementia.

BR2 C1: They wanted to know what my wishes were you know for him I didn't mention any of this to him and I don't think he knew I let them know.

3.3 | Human agency

Human agency represents how stakeholders interpret and respond to the identified intervention and contextual mechanisms. The most significant factor identified was the emotional difficulty that staff experienced in initiating discussions about death and dying.

3.3.1 | Emotion and reluctance to discuss death and dying

It was evident that some care home staff found it emotionally difficult delivering EoLC to residents, especially towards the end stages of their life. The emotional labour of delivering EoLC was expressed by a range of care home staff from housekeeping, to care assistants to registered nurses and managers with their years of experience ranging from 2–29 years.

Care assistant 2 C1: In some ways you become their family because you're spending more time with them than their family. Often families stay away as they don't want to see their loved one dying so often you take their place. You try being their family for them. So, losing a resident like that can be very emotional yes.

Housekeeping C3: We get very emotional because we get attached to them, you can't help that you're human.

It was apparent staff's emotional attachment to residents impacted on their ability to discuss death and dying as part of advanced care planning. Analysis implies that staff's close attachments with residents led to them feeling uncomfortable discussing sensitive and potentially upsetting topics, such as death and dying. Despite the reluctance to discuss death and dying it was well understood by all care home staff that advance care planning was part of their 'professional job', thus it was not avoided. However, it was evident throughout the transcripts that discussions about death and dying as part of advance care planning were sometimes rushed and overlooked.

Manager C2: We often shy away because we feel uncomfortable... But we really don't talk about that...we really don't explore that. So, it makes us come across as a bit stilted and a bit stiff.

Care assistant 3 C1: You just have to try to put it to the back of your mind. Although it's upsetting it is your professional job at the end of the day, you can't let it affect your work and how you are.

However, these quotes suggest that it is more than just care home staff's relationships with residents. This data uncovers a defence mechanism used by some care home staff which may be detrimental to residents and relatives. Specifically, the quotes imply that care home staff are avoiding discussions about death and dying, not only to prevent upset to residents, but to also protect themselves from upset.

This reluctance was noticed by bereaved relatives during phase 2 of the study. Specifically, they expressed how some staff would attempt to hide and avoid sensitive discussions about death and dying, pertaining to their own care and the care of other residents living in the care home.

BR2 C1: I noticed at the home people simply disappeared and we were all tactful enough not to ask. I think we were told they had gone to the hospital or something. I'm pretty sure they died in the night. I mean that's what they there for, let's face it.

4 | DISCUSSION

The findings of this study showed that although the importance of advance care planning was well recognized, the emotional labour of frequently engaging in discussions about death and dying was a problem for some care home staff. In some cases, care home staff's unmet emotional needs led them to rushing and avoiding discussions about death and dying with residents and relatives. Despite these difficulties, our findings indicated a sparsity of mechanisms to support care home staff's emotional needs. In addition, a lack of training and knowledge, particularly amongst non-registered care home staff and those with non-formal caring roles, appeared to inhibit their ability to engage in meaningful care planning conversations with those living with dementia due to preconceived assumptions and communication barriers.

Whilst the numbers of advance care plans in place are important (Finucane et al., 2013; Kinley et al., 2014; O'Sullivan et al., 2016; Temkin-Greener et al., 2017), findings presented in this study suggest that more needs to be done to support staff to sensitively engage in discussions about death and dying to improve the quality of advance care planning discussions.

Although current education mechanisms such as shadowing helped staff learn the practicalities of engaging in discussions about death and dying (such as how to approach the subject and what questions to ask), it was evident more needs to be done to support the emotional needs of care home staff. Specifically, findings identified that some care home staff were reluctant to talk about death and dying. Our findings indicated that care home staff's backgrounds, cultures and personal experiences influenced how they approached death and dying when delivering EoLC. Despite this, most literature advocates for supporting care home staff to manage the cultural needs and backgrounds of residents receiving EoLC (Givler & Patricia, 2019). However, only a few studies report on how care home staff's personal backgrounds and cultures can influence how they approach death and dying in the care home (Hall et al., 2011; Xiao et al., 2017). For example, Hall et al. (2011) highlighted a lack of confidence in staff from different cultures towards death and dying. Although, the findings from this present study support Hall and colleagues it was found that reluctance to talk about death and dying was experienced by many care home staff.

There was evidence to suggest that some care home staff's avoidance of conversations about death and dying was also about protecting their own emotional wellbeing. Specifically, analysis suggested that some care home staff avoided the subject of death and dying with residents as a defense mechanism. Similar behaviour has been found in professionals who are regularly exposed to emotional

and traumatic experiences (Drury et al., 2014). It has been found that being continually exposed to traumatic experiences without support can lead to compassion fatigue, which is described as a state of mental exhaustion triggered by a decreased ability to cope with everyday settings (Baranowsky & Gentry, 1999). Findings from this study suggest that care home staff's way of managing compassion fatigue was to avoid sensitive subjects with residents and relatives about death and dying. However, this behaviour (avoidance) appeared detrimental to care home staff's ability to engage in meaningful advance care planning conversations with residents and relatives.

Care home staff's reluctance to talk about death and dying was particularly apparent with residents with dementia. Some care home staff went straight to the next of kin to develop the advance care plan as they believed that residents with dementia would not understand and would become too upset if they discussed death and dying with them. This poses implications for practice not only because of the rising numbers of residents living with dementia in UK care homes (Alzheimer's Research UK, 2020), but because research has found that residents who are cognitively impaired such as those living with dementia have a greater chance of being unnecessarily admitted to hospital at the EoL (Perrels et al., 2014). These findings suggest that need to provide care home staff with the knowledge to be able to sensitively engage in discussions about death and dying with a diverse range of residents, including those with dementia.

Despite the need for more education and support, findings suggest that a lack of resources inhibited change. For example, despite the apparent emotional issues in the care home workforce, there was lack of educational focus on emotionally supporting staff to build resilience around advance care planning. This is important as care homes across the UK and Europe are struggling with limited resources, increasing demands and expectations (European Commission, 2018; The King's Fund, 2018). However, while costs need to be taken into account and minimized, the evidence presented in this study highlights important quality issues in the provision of advance care planning which justify the need for care homes to incorporate greater support for their workforce into their cost base.

4.1 | Limitations

The study did not include residents receiving EoLC. This is recognized as a limitation given that service users' perspectives and experiences are often overlooked (Spacey et al., 2020). Nonetheless, bereaved relatives were included in the study which provides valuable serve user insight whilst also acting as a proxy for residents themselves. The number of care homes involved in the study was also a limitation, three care home were selected, limiting the transferability and generalizability of the findings. However, these homes were carefully selected to represent the main care home types in England. This study did not explore the implementation of any specific intervention to support advance care planning, therefore inferences about causality cannot be made. Nonetheless, our

findings have highlighted some of the processes which may influence the effectiveness of care planning in advance of EoLC in care homes.

5 | CONCLUSION

Findings provide care home staff, policy makers, regulators and researchers with a deeper insight into what needs to be done to support advance care planning in care homes. For example, findings from our study suggest that more research and education initiatives need to go into supporting care home staff emotionally to improve their ability to engage in discussions about death and dying as part of advance care planning.

In the longer term, the findings generated in this study can be used to inform the development of future interventions designed to support care home staff engage in advance care planning. However, further research is recommended to replicate the study in different contexts such as rural care home settings to assess the generalizability of the findings.

CONFLICT OF INTEREST

No conflict of interest has been declared by the author(s).

AUTHOR CONTRIBUTIONS

All authors have agreed on the final version and meet at least one of the following criteria (recommended by the ICMJE*): (1) substantial contributions to conception and design, acquisition of data, or analysis and interpretation of data; (2) drafting the article or revising it critically for important intellectual content.

PEER REVIEW

The peer review history for this article is available at <https://publons.com/publon/10.1111/jan.14822>.

ORCID

Adam Spacey  <https://orcid.org/0000-0001-5833-6189>

Janet Scammell  <https://orcid.org/0000-0001-8489-239X>

Sam Porter  <https://orcid.org/0000-0002-6950-9388>

REFERENCES

- Aasmul, I., Husebo, S., Sampson, L., & Flo, E. (2018). Advance care planning in nursing homes – Improving the communication among patient, family, and staff: Results from a Cluster Randomized Controlled Trial (COSMOS). *Frontiers in Psychology, 9*, 2284. <https://doi.org/10.3389/fpsyg.2018.02284>
- Alzheimer's Research UK. (2020). *Statistics about dementia*. Retrieved from <https://www.dementiastatistics.org/statistics-about-dementia/>
- Andreasen, P., Finne-Soveri, H., Deliens, L., Van den Block, L., Payne, S., Gambassi, G., & Szczerbińska, K. (2019). Advance directives in European long-term care facilities: A cross-sectional survey. *BMJ Supportive & Palliative Care, bmjpspcare-2018-001743*. <https://doi.org/10.1136/bmjpspcare-2018-001743>
- Baranowsky, A., & Gentry, J. (1999). *Workbook/journal for a compassion fatigue specialist*. Psych Ink Resources.
- Bone, A., Gomes, B., Etkind, S., Verne, J., Murtagh, F., Evans, C., & Higginson, I. (2018). What is the impact of population ageing on the future provision of end-of life care? Population-based projections of place of death. *Palliative Medicine, 32*(2), 329–336. <https://doi.org/10.1177/0269216317734435>
- Braun, K., & Zir, A. (2005). Using an interactive approach to teach nursing home workers about end-of-life care. *Journal of Hospice & Palliative Nursing, 7*(5), 280–288. <https://doi.org/10.1097/00129191-200509000-00015>
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology, 3*(2), 77–101. <https://doi.org/10.1191/1478088706qp063oa>
- Cloninger, C. R. (2011). Person-centred integrative care. *Journal of Evaluation in Clinical Practice, 17*(2), 371–372. <https://doi.org/10.1111/j.1365-2753.2010.01583.x>
- Commission, E. (2018). Challenges in long-term care in Europe. Retrieved from <https://ec.europa.eu/social/main.jsp?langId=en&catId=89&newsId=9185>
- Competition & Markets Authority (CMA). (2017). *Care homes market study: CMA*. Retrieved from <https://assets.publishing.service.gov.uk/media/5a1fdf30e5274a750b82533a/care-homes-market-study-final-report.pdf>
- Cronfalk, B., Ternstedt, B., Larsson, L., Henriksen, E., Norberg, A., Österlind, J., & Österlind, J. (2015). Utilization of palliative care principles in nursing home care: Educational interventions. *Palliative and Supportive Care, 13*(6), 1745–1753. <https://doi.org/10.1017/S1478951515000668>
- Drury, V., Craigie, M., Francis, K., Aoun, S., & Hegney, D. G. (2014). Compassion satisfaction, compassion fatigue, anxiety, depression and stress in registered nurses in Australia: Phase 2 results. *Journal of Nursing Management, 22*, 519–531. <https://doi.org/10.1111/jonm.12168>
- Fisher, R., Ross, M., & MacLean, M. (2000). A guide to end of life care for seniors. *Journal of Palliative Care, 16*(4), 47–53.
- Finucane, A., Stevenson, B., Moyes, R., Oxenham, D., & Murray, S. (2013). Improving end-of-life care in nursing homes: Implementation and evaluation of an intervention to sustain quality of care. *Palliative Medicine, 27*(8), 772–778. <https://doi.org/10.1177/0269216313480549>
- Garden, G., Green, S., Pieniak, S., & Gladman, J. (2016). The Bromhead Care Home Service: The impact of a service for care home residents with dementia on hospital admission and dying in preferred place of care. *Clinical Medicine, 16*(2), 114–118. <https://doi.org/10.7861/clinmedicine.16-2-114>
- Givler, A., & Maani-Fogelman, P. A. (2019). *The importance of cultural competence in pain and palliative care*. Retrieved from <https://www.ncbi.nlm.nih.gov/books/NBK493154/>
- Griffiths, D., Fenton, W., Polzin, G., Price, R., Arkesden, J., & McCaffrey, R. (2019). *The state of the adult social care workforce within England*. Retrieved from <https://www.skillsforcare.org.uk/adult-social-care-workforce-data/Workforce-intelligence/documents/State-of-the-adult-social-care-sector/State-of-Report-2019.pdf>
- Hall, S., Goddard, C., Stewart, F., & Higginson, I. (2011). Implementing a quality improvement programme in palliative care in care homes: A qualitative study. *BMC Geriatrics, 11*(1), 31. <https://doi.org/10.1186/1471-2318-11-31>
- Kingston, A., Robinson, L., Booth, H., Knapp, M., & Jagger, C. (2018). Projections of multi-morbidity in the older population in England to 2035: Estimates from the Population Ageing and Care Simulation model. *Age & Ageing, 47*(3), 374–380. <https://doi.org/10.1093/ageing/afx201>
- Kinley, J., Stone, L., Dewey, M., Levy, J., Stewart, R., McCrone, P., Sykes, N., Hansford, P., Begum, A., & Hockley, J. (2014). The effect of using high facilitation when implementing the Gold Standards Framework in Care Homes programme: A cluster randomised

- controlled trial. *Palliative Medicine*, 28(9), 1099–1109. <https://doi.org/10.1177/0269216314539785>
- Kitson, A., Marshall, A., Bassett, K., & Zeitz, K. (2013). What are the core elements of patient-centred care? A narrative review and synthesis of the literature from health policy, medicine and nursing. *Journal of Advanced Nursing*, 69(1), 4–15. <https://doi.org/10.1111/j.1365-2648.2012.06064.x>
- Laing & Buisson. (2016). *Care of older people: UK market report* (27th ed.). Retrieved from https://www.laingbuisson.com/wp-content/uploads/2016/06/Care_OlderPeople_27ed_Bro_WEB.pdf.
- Leaman, L. (2011). *Nursing assistant: Role profile*. Retrieved from <https://www.stmonicatrust.org.uk/sites/default/files/Role%20profile%20NURSING%20CARE%20ASSISTANT.pdf>
- Lincoln, Y. S., & Guba, E. G. (1985). *Naturalistic inquiry*. Sage Publications.
- Mayrhofer, A., Goodman, C., Smeeton, N., Handley, M., Amador, S., & Davies, S. (2016). The feasibility of a train-the-trainer approach to end of life care training in care homes: An evaluation. *BMC Palliative Care*, 15, 1–8. <https://doi.org/10.1186/s12904-016-0081-z>
- McGlade, C., Daly, E., McCarthy, J., Cornally, N., Weathers, E., O'Caomh, R., & Molloy, D. (2017). Challenges in implementing an advance care planning programme in long-term care. *Nursing Ethics*, 24(1), 87–99. <https://doi.org/10.1177/0969733016664969>
- Murray, A., Kendall, M., Carduff, E., Worth, A., Harris, F., Lloyd, A., Cavers, D., Grant, L., & Sheikh, A. (2009). Use of serial qualitative interviews to understand patients' evolving experiences and needs. *British Medical Journal*, 339(7727), 958–960.
- National Health Service (NHS). (2018). *What end of life care involves*. Retrieved from <https://www.nhs.uk/conditions/end-of-life-care/what-it-involves-and-when-it-starts/>
- National Institute for Health and Care Excellence (NICE). (2019). *Advance care planning*. Retrieved from <https://www.nice.org.uk/Media/Default/About/NICE-Communities/Social-care/quick-guides/advance-care-planning-quick-guide.pdf>
- O'Sullivan, R., Murphy, A., O'Caomh, R., Cornally, N., Svendrovski, A., Daly, B., Fitzgerald, C., Twomey, C., McGlade, C., & Molloy, D. (2016). Economic (gross cost) analysis of systematically implementing a programme of advance care planning in three Irish nursing homes. *BMC Research Notes*, 9, 1–10. <https://doi.org/10.1186/s13104-016-2048-9>
- Perrels, A., Fleming, J., Zhao, J., Barclay, S., Farquhar, M., Buiting, H., & Brayne, C. (2014). Place of death and end-of-life transitions experienced by very old people with differing cognitive status: Retrospective analysis of a prospective population-based cohort aged 85 and over. *Palliative Medicine*, 28(3), 220–233. <https://doi.org/10.1177/0269216313510341>
- Porter, S. (2015). Realist evaluation: An immanent critique. *Nursing Philosophy*, 16(4), 239–251. <https://doi.org/10.1111/nup.12100>
- Rietjens, J. A. C., Sudore, R. L., Connolly, M., van Delden, J. J., Drickamer, M. A., Droger, M., van der Heide, A., Heyland, D. K., Houttekier, D., Janssen, D. J. A., Orsi, L., Payne, S., Seymour, J., Jox, R. J., & Korff, I. J. (2017). Definition and recommendations for advance care planning: An international consensus supported by the European Association for Palliative Care. *The Lancet Oncology*, 18(9), E543–E551. [https://doi.org/10.1016/S1470-2045\(17\)30582-X](https://doi.org/10.1016/S1470-2045(17)30582-X)
- Sharp, T., Moran, E., Kuhn, I., & Barclay, S. (2013). Do the elderly have a voice? Advance care planning discussions with frail and older individuals: A systematic literature review and narrative synthesis. *British Journal of General Practice*, 63(615), E657–E668. <https://doi.org/10.3399/bjgp13X673667>
- Spacey, A., Scammell, J., Board, M., & Porter, S. (2018). End-of-life care in UK care homes: A systematic review of the literature. *Journal of Research in Nursing*, 1–21. <https://doi.org/10.1177/1744987118757839>
- Spacey, A., Scammell, J., Board, M., & Porter, S. (2020). Systematic critical realist review of interventions designed to improve end-of-life care in care homes. *Nursing & Health Sciences*, 22(2), 343–354. <https://doi.org/10.1111/nhs.12665>
- Sudore, R., Lum, H., Hanson, L., Meier, D., Pantilat, S., & Heyland, K. (2016). Defining advance care planning for adults: A consensus definition from a multidisciplinary Delphi Panel (S740). *Journal of Pain and Symptom Management*, 53(2), 431–432.
- Temkin-Greener, H., Mukamel, D. B., Ladd, H., Ladwig, S., Caprio, T. V., Norton, S. A., Quill, T. E., Olsan, T. H., & Cai, X. (2017). Impact of nursing home palliative care teams on end-of-life outcomes: A randomized controlled trial. *Medical Care*, 56(1), 11–18. <https://doi.org/10.1097/MLR.0000000000000835>
- The Gold Standards Framework (GSF). (2018). *Patients & carers*. Retrieved from <https://www.goldstandardsframework.org.uk/what-are-gold-or-gsf-patients>
- The King's Fund. (2018). *Key challenges facing the adult social care sector in England*. Retrieved from <https://www.kingsfund.org.uk/sites/default/files/2018-12/Key-challenges-facing-the-adult-social-care-sector-in-England.pdf>
- The Mental Capacity Act (MCA). (2005). *The Mental Capacity Act 2005* [online]. Office of public guardian. Retrieved from <https://www.legislation.gov.uk/ukpga/2005/9/contents>
- Tong, A., Sainsbury, P., & Craig, J. (2007). Consolidated criteria for reporting qualitative research (COREQ): A 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*, 19(6), 349–357. <https://doi.org/10.1093/intqhc/mzm042>
- Tongco, M. C. (2007). Purposive sampling as a tool for informant selection. *Ethnobotany Research and Applications*, 5, 147–158. <https://doi.org/10.17348/era.5.0.147-158>
- United Nations (UN) (2017). *Population aging and sustainable development*. United Nation, Population division. Retrieved from Microsoft Word - PopFacts_Ageing and development_2017_With John Edits_june16.docx.
- World Health Organisation (WHO). (2017). *Global strategy and action plan on ageing and health*. Retrieved from <https://www.who.int/ageing/WHO-GSAP-2017.pdf?ua=1>
- Xiao, L., Willis, E., Harrington, A., Gillham, D., De Bellis, A., Morey, W., & Jeffers, L. (2017). Resident and family member perceptions of cultural diversity in aged care homes. *Nursing and Health Sciences*, 19(1), 59–65.

How to cite this article: Spacey A, Scammell J, Board M, Porter S. A critical realist evaluation of advance care planning in care homes. *J Adv Nurs*. 2021;00:1–11. <https://doi.org/10.1111/jan.14822>

The *Journal of Advanced Nursing (JAN)* is an international, peer-reviewed, scientific journal. *JAN* contributes to the advancement of evidence-based nursing, midwifery and health care by disseminating high quality research and scholarship of contemporary relevance and with potential to advance knowledge for practice, education, management or policy. *JAN* publishes research reviews, original research reports and methodological and theoretical papers.

For further information, please visit *JAN* on the Wiley Online Library website: www.wileyonlinelibrary.com/journal/jan

Reasons to publish your work in *JAN*:

- High-impact forum: the world's most cited nursing journal, with an Impact Factor of 2.561 – ranked 6/123 in the 2019 ISI Journal Citation Reports © (Nursing; Social Science).
- Most read nursing journal in the world: over 3 million articles downloaded online per year and accessible in over 10,000 libraries worldwide (including over 6,000 in developing countries with free or low cost access).
- Fast and easy online submission: online submission at <http://mc.manuscriptcentral.com/jan>.
- Positive publishing experience: rapid double-blind peer review with constructive feedback.
- Rapid online publication in five weeks: average time from final manuscript arriving in production to online publication.
- Online Open: the option to pay to make your article freely and openly accessible to non-subscribers upon publication on Wiley Online Library, as well as the option to deposit the article in your own or your funding agency's preferred archive (e.g. PubMed).