Title: A Systematic Critical Realist Review of Interventions Designed to Improve End of Life Care in Care Homes.

Abstract:

The demand for high quality end of life care is rising. Frequently evidenced concerns about the provision of end of life care in care homes relate to interdisciplinary communication and engagement in advance care planning. A number of interventions employing different mechanisms have been designed to address these issues. The aim of the systematic critical realist review was therefore to describe and explain the effectiveness of interventions designed to improve end of life care in care homes. Electronic searches were conducted in ScienceDirect; MEDLINE; PubMed; PsychINFO and CINAHL from January 2000 – August 2018. 41 studies were included in the review. While most of the evidence identified in this review was not strong, there was evidence to suggest that education and interprofessional collaboration can be effective intervention mechanisms for improving end of life care in care homes. High staff turnover was a significant contextual mechanism impacting on the sustainability of interventions. In terms of human agency, it is important to note a consistent finding related to the dedication and enthusiasm of care home staff who deliver end of life care.

KEYWORDS: Terminal care, palliative care, nursing homes, residential facilities, systematic review, education.

1 INTRODUCTION

The population is ageing in all economically developed countries (UN, 2017), leading to increased numbers approaching the end of life (EoL) with complex symptoms, morbidities and trajectories of dying (Julien & Jose-Luis, 2011; World Health Organisation, 2011). This is placing increasing pressures on care home settings to deliver high quality EoLC. For example, deaths in England and Wales have been predicted to increase from 501,424 in 2014 to 635,814 in 2040, by which time care homes are predicted to become the most common place of death (Bone et al., 2018). Similar increases have also been evidenced in other developed countries such as Spain, Italy and the Netherlands (UN, 2017; Statistics Bureau, 2018), with Spain expected to see the greatest rise in its population aged over 65 years in the next 40 years to 2060, from 20.4% to 35.3% (National Statistics office, 2016). However, the ageing population is not unique to Europe, but is a global phenomenon. While Europe and North America are the continents with the highest proportions of older people, more older people reside in Asia (UN, 2017). For example, Japan is currently the leading nation in this respect with 25.9% of its population being aged 65 years or older and 12.5% of the population being age 75 (Statistics Bureau, 2018). However, countries such as China are not far behind with 9.5% of its current population being aged 65 or over with this expected to reach 27.4% by 2050 (Centre for Strategic and International Studies, 2019).

In light of the increasingly ageing populations and people’s preferences to die at home, government policies around the world have supported older people to die in community settings such as care homes (Bone et al., 2018; Japanese Government, 2015). Thus, the ageing populations pose significant challenges to staff providing EoLC in care homes (Annear et al., 2016). Despite the increasing demands on care homes to deliver EoLC around the world, recent research has suggested that standards of EoLC delivery vary between care homes (Pivodic et al., 2018; [redacted]. The most frequently evidenced issues in the provision of end of life care in care homes relate to poor interdisciplinary communication between services [redacted], preparedness for sudden and unexpected declines of residents (Kinley et al., 2018; Barclay et al., 2014), engagement in advance care planning and discussions about death and dying (Shimada et al., 2016; Irene et al., 2018), and unnecessary admissions to hospital at the EoL (Harrison et al., 2016). A number of interventions have been designed to address these problems in care homes.

However, current studies have reported that there is a need to develop more effective interventions to address common concerns about EoLC in care homes (Spilsbury et al., 2015; Anstey et al., 2016; Vandrevala et al., 2016). Complex interventions are frequently used in health and social care practice and are defined by the Medical Research Council (MRC) as interventions that are made up of multiple and interacting components (MRC, 2006). Exploring how these components interact and are influenced by context can help evaluators in the design of interventions (Moore et al., 2015). However, currently there is no systematic overview of current interventions designed to improve EoLC in care homes. Thus, before future interventions are designed there is a need for research to systematically evaluate the effectiveness of current interventions deigned to improve EoLC in care homes. Moreover, rather than simply identifying outcomes, there is a need to explore the processes behind those outcomes, including the barriers to and facilitators of high quality EoLC, in order to inform the design of interventions operating in care home contexts.

2 Aims and objectives

The aim of this review is to describe and explain the effectiveness of interventions designed to support end of life care in care homes. In order to achieve this aim the following objectives were set:

- To identify theories in the literature about how interventions support EoLC in care homes work (intervention mechanisms).
- To identify how the context of care homes influence how interventions work (contextual mechanisms).
- To identify how the various stakeholders tend to respond to interventions in the context of EoLC in care homes (human agency).
- To identify the outcomes resulting from the interventions.

3 Methods

In order to achieve the aims and objectives of the review, a systematic critical realist review methodology was chosen. Central to critical realism is a rejection of the assumption that the effectiveness of an intervention is based only on its inherent qualities. Critical realism instead proposes that outcomes result from complex interactions of causal mechanisms which differ according to context (Blackwood et al., 2010). Mechanisms are embedded in both the intervention itself and in the social and organisational context in which the intervention is introduced (in this case care homes). Moreover, these mechanisms are filtered through people, who have an ability to interpret and respond to them differently. Therefore, evaluation of an intervention's effectiveness should include how different people experience and respond to it and why (Porter, 2015a). This process is detail in figure 1 below:

[Figure 1 here]

This approach to evaluating the effectiveness of interventions designed to improve EoLC can be summed up by using the following formula: intervention mechanisms + contextual mechanisms + human agency = Outcome (see table: 1) (Porter, 2015b). Adhering to this formula, the review identifies the mechanisms built into interventions designed to improve EoLC. It then explores how these mechanisms are supported or inhibited by contextual mechanisms within the care home context. These mechanisms are then analysed in terms of evidence about how people experience and respond to them. Finally, the review explores the outcomes that result from the interaction between intervention mechanisms, contextual mechanisms and human response (Porter, 2015a; Porter, 2015b). This review was designed in accordance to the RAMESES guidelines (Wong et al., 2013).

[Table: 1 here]

3.1 Search strategy

A rigorous systematic PRISMA approach was used (See Supplementary File 1) to search for relevant literature to inform the review (Moher et al., 2009). The search strategy aimed to identify relevant literature that described and evaluated complex interventions designed to support EoLC in care homes. Preliminary searches were conducted using the EBSCO database. This provided insight into key terminology and relevant databases. Following on from the preliminary search, four main databases were systematically searched: ScienceDirect; MEDLINE; PubMed; PsychINFO and CINAHL. These databases were included because they had been identified in the preliminary search as containing the journals relevant to the research topic. The search also included manual searching of the reference lists of papers and hand searching of the grey literature. Boolean techniques (Table: 2) were used to help capture relevant literature (Gerrish & Lathlean, 2015).

This search was conducted on 25th August 2018. It included studies relating to EoLC interventions in care homes (both nursing and residential homes), dated from January 2000 to August 2018. Using this search strategy, the key components were entered into the database with their alternative subject headings (Table: 2). The electronic databases were searched from 2000 to August 2018. No location restrictions were implemented. The purpose of having no location restrictions and a large date range was to include a wider range of relevant empirical studies exploring EoLC interventions in care homes internationally.

[Table: 2 here]

3.2 Eligibility criteria

The review includes primary research studies evaluating complex interventions aimed at supporting EoLC in care homes internationally. These included both nursing and residential care homes. Interventions operating in hospices or hospitals were excluded. Policy documents were also excluded.

All included studies were written in English and published from 2000-August 2018. Types of participants included in this review were aged care residents, relatives, bereaved relatives, care home staff including managers, registered nurses and care assistants. Studies which include healthcare professionals alongside the participants listed above were included.

3.3 Study screening process

The data extraction was carried out by AS, and cross-checked by SP, JS and MB to minimise selection bias (Holloway & Galvin, 2017). The initial process chosen for data extraction was title screening. All the articles were assessed and only the titles relevant to the review were selected. However, if titles did not contain enough information to make a judgment, the articles were included and filtered in later processes. Following title screening, abstract screening commenced, which involved a detailed reading of each abstract. Only abstracts which met the inclusion and exclusion criteria were included (See section 3.2 and figure: 2~~1~~). Again, if the abstract only included limited information, the study was included and filtered in later processes.

3.4 Quality appraisal

The Critical Appraisal Skills Programme (CASP) was used to assess the quality of the included studies (CASP, 2018). A numerical assignment of 0, 1 or 2 was awarded according to how effectively the study answered the questions (0=no, 1=not sure, 2=yes). Qualitative studies were rated out of 20, quantitative studies were rated out of 22, and randomised controlled trials were rated out of 22 and cohort studies were rated out of 24. Quality assessment was carried out by AS and cross-checked by SP, JS and MB. The overall quality of the studies was moderate (table 3). No studies were excluded on the grounds of quality assessment as the aim of this review was to uncover theories of change and to capture rich detail on processes which may influence outcomes.

3.5 Data extraction and synthesis

Following title and abstract screening, the resultant full-text evidence was read by AS, MB, SP and JS. Articles were included if they met the inclusion and exclusion criteria. See figure 2~~1~~ for a breakdown of the included articles and the process of filtration. The included articles were weighted on their ability to provide rich detail on mechanisms, context and agency and how these processes influence interventions.

AS carried out data synthesis and thematic analysis (Braun and Clarke, 2006). The data was coded and reoccurring patterns were noted and organised into sub-themes and themes. In depth realist synthesis (Wong et al., 2013) was then used to conceptualise and arrange the thematically analysed data in accordance to mechanisms and agency. Independent thematic analysis of selected articles was carried out by SP in order to optimise robustness by means of triangulation.

[Figure: 2~~1~~ here]

4 Results

4.1 Description of articles

41 studies pertaining to 34 different interventions were included. 26 of the studies were UK-based, 11 from the USA, three from Sweden, and one from Ireland. Interventions were predominately implemented into nursing homes (n=35) with only two studies specifically focusing on residential homes and four focusing on both nursing and residential homes.

4.2 Participants

Participants in most studies were care home staff (n=35/41), including care assistants, care home managers, registered nurses, doctors and palliative care specialists. Fewer studies included residents (n=8), relatives (n=4) and bereaved relatives (n=3). Six interventions also involved case note analysis of deceased residents.

4.3 Intervention mechanisms

This section identifies the mechanisms contained in the interventions that were designed to change the behaviour of those at whom the intervention was aimed.

All of the included interventions contained mechanisms related to education, although their educational focus differed, including:

- EoL discussions with residents and relatives and advance care planning (n=19);
- Leadership and communication with external services (n=10);
- Overarching principles such as person-centred and dignified EoLC (n=12);
- Education on identifying the signs and symptoms of the EoL (n=4);
- Dementia education (n=5);
- Symptom and pain management (n=8).

As can be seen from the numbers above interventions often included more than one educational focus. For example, some interventions included both education on the overarching principles of EoLC and advanced care planning (Farrington et al., 2014; Cox et al., 2017; Dobie et al., 2016), while others focused on education related to advanced care planning for residents with dementia (Livingston et al., 2013; Garden et al., 2016). The majority of the educational interventions were designed for registered nursing staff. Seven studies provided education for non- registered care home staff (Baron et al., 2015; Dowding, and Homer, 2000; Farrington, 2014; Hall et al., 2011; Kunte et al., 2017; Brännström et al., 2016; Kinley et al., 2017), and only one study was explicit about providing education for non-registered staff, such as housekeeping and administrative staff, who did not have a clinical role (Badger et al., 2012).

In most studies (n=35) it was hypothesised that education was the most effective mechanism to address the common issues associated with EoLC. For example, O’Sullivan et al., (2016) identified residents not having advance care plans in place as a problem which persisted because care home staff lacked the knowledge and confidence to engage in advance care planning. Therefore, they used education to provide care home staff with the knowledge and confidence to effectively engage in advance care planning. Similarly, Arcand et al., (2009) noted that communication between care home staff and residents living with dementia was poor due to staff's lack of knowledge of the symptoms of dementia. Consequently, education on symptom of dementia was used to improve staff's knowledge and ability to communicate more effectively with residents with dementia.

Education tended to be delivered through either a fixed number of sessions or as an ongoing process. 29 studies evaluated time-limited interventions, while 11 studies evaluated ongoing interventions (each intervention is described in table 3). The most significant intervention in the UK, the Gold Standards Framework for Care Homes (GSFCH) offers ongoing access to educational content (Badger et al., 2012; Finucane et al., 2013; Hall et al., 2011). It was hypothesised that the ongoing design enabled the educational content to be updated and evolve over time to meet the changing needs of the care homes and their workforce (Kinley et al., 2017; Badger et al., 2012). However, most interventions were designed to deliver a fixed amount or length of education (n=29) with the shortest being one away day (Dobie et al., 2016) and the longest being 35 workshops over two years (Finucane et al., 2013). For example, Livingston et al., (2013) delivered ten education sessions, while Cox et al., (2017) delivered 18 sessions. Only one study provided a clear rationale for the length of delivery. Dobie et al., (2016) delivered education over a one day period, justifying this length on the grounds of the limited time available to staff for EoLC training.

While there was a lack of explicit rationales for the length of delivery, the mode of education delivery appeared to influence length. Modes of delivery included workshops, peer-training, online modules, lectures, action learning and away days. Peer-training and action learning tended to be delivered on a longer and more ongoing basis (Finucane et al., 2013; O'Brien et al., 2016; Kinley et al., 2014; Hockley et al., 2005). Conversely, interventions consisting of lectures and away-days tended to be 'short lived' in comparison (Dobie et al., 2016; Parks et al., 2005; Wen et al., 2012; Garden et al., 2016; Cox et al., 2017; Livingston et al., 2013). The use of educational workshops varied in length from three workshops (Mayrhofer et al., 2016) to 35 workshops (Finucane et al., 2013).

Other non-educational mechanisms included the introduction of formalised reflective practice sessions which gave staff the opportunity to reflect on their practice or an event such as a death. However, only three studies briefly discussed reflection, all involving reflective sessions with home managers (Hockley et al., 2014; Nash and Fitzpatrick, 2015; Cox et al., 2017; Hewison, Badger and Swani, 2011). These studies reported that reflection encouraged staff to understand what they did well and how they could improve their EoLC delivery. However, there was no rationale for confining the facilitation of reflection to managers.

The introduction of external professionals into care homes to help facilitate and support interventions was a common mechanism used (Kinley et al., 2014; Temkin-Greener et al., 2017; Finucane et al., 2013; Kinley et al., 2018). For example, Finucane et al., (2013) introduced two palliative care specialist nurses to facilitate training and to support care home staff deliver EoLC and help with aspects such as collaboration. ~~Similarly, Temkin-Greener et~~

4.4 Contextual mechanisms

Contextual mechanisms represent the resources and restrictions embedded in the social and organisational context which may inhibit or promote the effectiveness of intervention mechanisms.

While the rationale for only including a limited amount of education sessions and the lack of multicomponent interventions was not clear in any of the included studies, two studies implied that it was to ensure that interventions were manageable for the care home, many of which were small organisations with limited funding and resources. The implication was that the resource and financial capabilities of care homes impacted on their ability to engage with interventions requiring extended time and resources (Kinley et al., 2017; Hewison, Badger & Swani, 2011). Thus, Hewison, Badger & Swani's (2011) intervention was terminated due to the lack of time and resources of care home managers to engage in 'active learning meetings'. Furthermore, a number of other studies noted that existing work schedules of care home staff impacted on sustainability. It was found that care home staff often had to create time to engage with an intervention (Braun & Zir, 2005; Waldron et al., 2008; Phillips et al., 2008;

Mayrhofer et al., 2016; McGlade et al., 2017; Froggatt et al., 2017b), and lack of time for staff to engage with the interventions was a common barrier to implementing and maintaining effective change (Aida et al., 2013). For example, Dobie et al., (2016) only delivered one study day as it was the only period of time managers and staff felt they could accommodate. However, in the majority of studies the rationale for the length and mode of education was absent.

Kinley et al., (2017) found that offering a fixed or small amount of education sessions was not effective in care homes with high staff turnover, as knowledge and skills were not sustained because of the high staff churn rate. Kinley et al. (2017) identified ongoing education as necessary to sustaining and embedding knowledge in contexts where staff turnover is high. This was supported by an earlier study conducted by Kinley et al., (2014) which found that the three care homes included in the intervention which reported increases in hospital deaths, experienced managerial change.

The organisational structures of care homes were similar. Specifically, the size of the workforce was often small, meaning that interventions such as education sessions could reach and impact the whole workforce relatively easily and quickly (Nash & Fitzpatrick, 2015; Hewison, Badger & Swani, 2011; Hall et al., 2011; Mayrhofer et al., 2016). However, the small workforce also posed problems because knowledge and skills tended to be concentrated in fewer individuals, so when those individuals left the care home, their repository of knowledge was lost (Finucane et al., 2013; Kinley et al., 2014).

Despite similarities, there were also differences noted in the organisational structure of care homes. Kinley et al., (2017) highlighted that, because residential homes did not employ registered nurses, they tended to have an increased reliance on GPs and district nurses (Kinley et al., 2017). This meant that education content aimed at residential care home staff tended to be related to collaboration and was non-specialist to meet the need of non-registered care home staff (O'Brien et al, 2016; Mayrhofer et al, 2016; McGlade et al., 2017; Dobie et al., 2016; Kinley et al., 2017).

The workloads of those at whom the interventions were aimed was found to influence their ability to engage in interventions. In particular, Hewison, Badger & Swani, (2011) and Aida et al., (2013) set up collaborative meetings which gave care home managers the opportunity to discuss common issues related to EoLC and share experiences and knowledge. However, the lack of time of home managers negatively influenced their engagement in the meetings (Hewison, Badger & Swani, 2011; Aida et al., 2013). For example, Hewison, Badger & Swani, (2011) reported that all 22 care homes involved in the intervention decided not to continue with the meetings due to the high workloads of their managers, thus the intervention was not sustained.

4.5 Human agency

Human agency represents stakeholders' responses, interpretations and experiences of the contextual and intervention mechanisms.

Care home staff involved in the interventions were frequently described as being passionate and engaged, and driven by a desire to improve the experiences of families and residents receiving EoLC (Braun & Zir, 2005; Casarett et al., 2005; Dobie et al., 2016; Farrington, 2014; Froggatt et al., 2017b). It appeared that this passion also came from a desire for self-improvement through knowledge and learning (Dobie et al., 2016; Mayrhofer et al., 2016; Froggatt, 2000; Keay et al., 2003; Kunte et al., 2017).

Nonetheless, motivation did not always translate into engagement. Specifically, studies reported that the ability of care home staff to cascade knowledge varied (O'Brien et al., 2016; Finucane et al., 2013; Mayrhofer et al., 2016). For instance, it was found that care home staff were often too junior or not ready to receive training at a particular level, and thus were unable to effectively cascade knowledge to other care home staff because they did not have the confidence and knowledge to do so (O'Brien et al., 2016). This may be a particular issue for homes with high staff turnover, which leads to an increased reliance on junior or new staff (O'Brien et al., 2016; Kinley et al., 2017; Mayrhofer et al., 2016).

At a more senior level, lack of motivation may result from less commitment being given to EoLC in comparison to other activities. Thus, for example, the lack of engagement of care home managers in collaborative meetings due to lack of available time, also indicates that they gave EoLC a lower priority than other aspects of their role.

Additionally, some care staff found the application of what they learnt into real-world practice emotionally difficult (Mayrhofer et al., 2016; Braun & Zir, 2005; McGlade et al., 2017; Cox et al., 2017). For example, Hockley et al., (2005) found that in most of the eight care homes involved in the intervention, a culture of dealing covertly with death and dying reduced staff's confidence to discuss death with residents. Similarly, despite going through education and training on ACP and engaging in conversations about dying, some staff still found talking about dying challenging (Cronfalk et al., 2015; Mayrhofer et al., 2016; Braun & Zir, 2005; Temkin-Greener et al., 2017; McGlade et al., 2017). It was reported that staff's personal backgrounds and experiences could influence their ability to discuss dying with residents and relatives (Hall et al., 2001; Cox et al., 2017). For example, Hall et al., (2011) found that some staff's personal background and culture caused them to look at death as a taboo subject.

Similarly, residents and relatives also tended to experience and react to dying and EoLC differently, which again appeared to be influenced by their personal background and experiences. For example, some relatives were reported as not supporting the notion of planning for their relatives' death (Livingston et al., 2013; Casarett et al., 2005; Hall et al., 2011). Moreover, conflict amongst relatives regarding care and decisions about care was another issue. This conflict tended to arise when relatives were 'not ready', 'not accepting', or 'not understanding' about approaching death, and often would not 'give up' (Nash & Fitzpatrick, 2015).

As well as conflict within care homes, conflict was also apparent between care home staff and external services. Despite intervention mechanisms to encourage collaboration, external services staff, particularly out of hours (OOH) services such as OOH GPs were in some cases unwilling to cooperate due to negative attitudes toward care home staff (Badger et al., 2012; Kinley et al., 2014; Ashton et al., 2010). For instance, it was reported that OOH service staff tended not to advise or listen to care homes, but instead overrode their decisions (with a belief that they knew better than the care home), with a tendency to admit residents living with frailty to hospital at the end of their lives (Badger et al., 2012; Kinley et al., 2014). However, by way of qualification, it should be noted that these studies relied on information from care home staff and did not include the perspectives of OOH staff.

4.6 Outcomes

Outcome measures can be split into two main categories: objective and self-reported outcomes. Objective outcomes included the number of ACPs completed, place of death, numbers of unnecessary hospital admissions and cardiopulmonary resuscitation requests. These were recorded in 14 studies. Self-reported outcomes included levels of confidence and knowledge when delivering EoLC. Most studies (n=27) measured self-reported outcomes.

Subjective self-reported outcome measures such as self-proclaimed improvements in knowledge and confidence tended to be positive, while objective outcome measures such as place of death were more mixed and poorer in comparison. An example of objective measurement can be found in Temkin-Greener et al.'s, (2017) evaluation of the introduction of palliative care teams into care homes to support and educate care home staff. No statistically significant differences between the treatment and the control arms in any quality measures (which included place of death and number of hospitalisations) were reported during three years of their intervention.

In contrast, results relating to subjective outcome measures of ongoing interventions tended to be more positive. For example, O'Brien et al.'s (2016) evaluation of the "six steps to success" intervention reported improvements in staff's confidence and knowledge. Similarly, studies evaluating the GSFCH reported positive subjective outcome measures such as perceived benefits and improvements in knowledge and confidence (Hall et al., 2011; Badger et al., 2012; Nash and Fitzpatrick, 2015). Nonetheless, Kinley et al., (2014) and Hockley et al., (2010) both reported increases in advance care planning documentation during the GSFCH programme. However, Kinley et al., (2014) reported that high facilitation such as consistent managerial support and leadership was needed to maintain these outcomes. In homes which were not exposed to high facilitation only 7% (n=1/11) completed the GSFCH programme through to accreditation.

Differences in outcomes were also related to the time points at which they were measured. It was common practice to confine measurement of outcomes to the period during which interventions were running or shortly after their completion (Dobie et al., 2016; Baron et al., 2015; Farrington, 2014; Finucane et al., 2013; Wen et al., 2012; Mayrhofer et al., 2016; Hewison, Badger and Swani, 2011; Cox et al., 2017; Braun & Zir, 2005). This is significant because studies measuring immediate outcomes tended to report more positive outcomes than studies measuring longer term outcomes. For example, Farrington, (2014) reported improvements in care home staff's confidence, in symptom management and communication after only six modules of education, each taking an hour to complete. Moreover, Dobie et al.,

(2016) reported increases in staff's knowledge and confidence following only one study day. Short-term improvements were also noted in objective measurements. O'Sullivan et al. (2016) implemented a palliative care educational programme consisting of four half-day workshops for 90 staff in three nursing homes. Immediate outcomes suggested improved staff knowledge and confidence with higher uptake of advance care plans, resulting in a decreased percentage of hospital deaths from 22.9% to 8.4%, $z = 3.22$, $p = 0.001$. However, the sustainability of these interventions over time was rarely established because few of the included studies evaluated the effectiveness of interventions for long beyond the time of implementation or completion. This is important because most interventions (n=29) delivered time-limited or brief stints of education.

The few studies which measured outcome over longer periods of time reported poorer outcomes over time, even when the intervention was still in place. For example, Finucane et al., (2013) reported that, following the delivery of 35 workshops over two years, the proportion of deceased residents with ACPs in place, and the proportion of those with Do Not Attempt Cardiopulmonary Resuscitation (CPR) documentation in place increased but, reductions in admissions from care homes at the EoL to hospitals were not sustained.

Subjective and objective outcome measures were reported in studies evaluating multicomponent interventions. Compared to isolated educational interventions, studies evaluating multicomponent interventions tended to report more positive outcomes. For example, results highlight increases in ACPs as well as increases in care home staff's perceived knowledge and confidence, and improved collaboration and networking between services (Hall et al., 2011; Badger et al., 2012; Kingly et al., 2014; Nash and Fitzpatrick, 2015). However, given the lack of longitudinal data, the sustainability of these outcomes is uncertain.

In sum, outcomes were generally measured immediately after or during the running period of time-limited interventions, which tended to produce better outcomes compared to studies which measured outcomes over longer periods of time. Moreover, most studies reported subjective outcomes measures, which tended to be more positive in comparison to objective measures. Because most studies reported subjective outcome measures over short periods of time, sustainability of outcomes is unclear, and the effectiveness of most interventions may not have been as great as has sometimes been represented. Figure 3 below helps to illustrate how mechanisms and agency can influence outcomes.

[Figure 3 here]

5 DISCUSSION

By exploring the interrelation between mechanisms, agency and outcomes, a number of key insights were identified. It was revealed that, despite the effectiveness of multicompetent interventions, they were less frequently delivered than interventions using isolated components such as education only. This suggests that contextual mechanisms such as limited resources, high workloads and high staff turnover led to the adoption of single ‘short-lived’ interventions on pragmatic grounds rather than effectiveness criteria. This hypothesis is reinforced by the fact that the pragmatic adoption of less effective interventions in the care of this population is not confined to end-of-life care. Thus, for example, Bunn et al.’s, (2015) systematic review of hydration interventions for people with dementia found that, while multicomponent interventions were more effective, they were rarely delivered.

In an attempt to meet the contextual needs of care homes, education was delivered in a number of different ways which impacted on effectiveness. Although education delivery has been identified as an effective method to address many of the problems highlighted with current EoLC provision in care homes (Nevis, 2014), this review uncovered a huge variation in the ‘dosage’ entailed in different educational interventions. This disparate approach towards EoLC education and training for care home staff is unsurprising given that in most countries, including the UK, there are no specific recommendations about the appropriate amount of formal EoLC education (Froggatt et al., 2017a; WHO, 2011; DH, 2008). At present, there is a lack of policy guidance for care homes on how much and which mode of education delivery should be used to deliver EoLC education.

Moreover, studies did not evaluate their effectiveness long enough after the education had been completed to assess the sustainability of outcomes. Studies evaluating ongoing education interventions tended to measure outcomes over longer time periods (Temkin-Greener et al., 2017; Kinley et al., 2014; Badger et al., 2012). These showed some evidence that effectiveness diminished over time according to some indicators (Temkin-Greener et al., 2017; Kinley et al., 2014; Finucane et al., 2013). However, there is insufficient evidence to draw definite conclusions about the relationship between length of education delivery and sustainability.

High staff turnover was the most common contextual mechanism reported in the studies as compromising the effectiveness of interventions (Badger et al., 2012; Nash and Fitzpatrick, 2015; Kinley et al., 2014; Hewison, Badger and Swani, 2011). However, although staff turnover in care home across the globe is typically high (Halter et al., 2017; Tilden et al., 2012). However, Gatherum, (2017) provides evidence which suggests that often staff who leave homes tend not to leave the social care sector, but move to other nearby homes. This suggests that interventions delivered in multiple homes could be more sustainable by virtue of having cross-pollination of staff. However, although some studies in this review included up to 37 homes, most interventions were implemented in fewer than five care homes (see table 3).

Despite acknowledging workloads and high staff turnover, the included studies did not reflect the diverse context of care homes. For example, one important contextual factor that has not being given adequate attention is the type of care home. Most interventions were designed for nursing homes (n=35) with only two studies focusing only on residential homes (Brännström et al., 2016; Kinley et al., 2017) and four focusing on both nursing and residential homes (O'Brien et al, 2016; Mayrhofer et al, 2016; McGlade et al., 2017). This lack of attention to the specific context of residential homes is concerning, given that they usually do not have on-site registered nursing staff and, as a consequence have to rely more on external support from GPs and hospitals and visits from district nurses (Handley et al., 2014; Davies et al., 2011). Moreover, most interventions were designed for registered nursing staff, while much fewer offered education to non-registered care home staff (Baron et al., 2015; Dowding, and Homer, 2000; Farrington, 2014; Hall et al., 2011; Kunte et al., 2017), and even less to those such as housekeeping and administrative staff, who did not have a clinical patient care role (Badger et al., 2011). There is therefore a need to better illustrate the diverse contextual mechanisms present in care homes, and the potential impact on the effectiveness of interventions in future studies.

~~A recent survey carried out by the Marie Curie Palliative Care Research Centre, (2017) reported that poor relationships persisted between care home staff and hospice specialists because of the high staff turnover in care homes impacting the continuity and longevity of relationships. The effects of such contextual factors on human agency needs to be taken into account in the design of future interventions aiming to improve collaboration between services.~~

Despite limited evidence, this review was able to identify how those involved tended to respond to the intervention and contextual mechanisms. One aspect that the studies are largely agreed upon is that motivation is not a significant problem. Evidence suggests the majority of care home staff were highly engaged and motivated to provide high quality EoLC (Braun & Zir, 2005; Casarett et al., 2005; Dobie et al., 2016; Farrington, 2014; Froggatt et al., 2017b). This finding appears to be consistent across other healthcare settings such as hospices and hospitals, which report that delivering EoLC can be rewarding and satisfying if done well (Gillman et al., 2012; Hospice UK, 2015).

Nonetheless, results indicated that while care home staff found delivering EoLC rewarding they also found it emotionally challenging, especially in relation to discussing death and dying (Hall et al., 2011; Braun & Zir, 2005; Hockley et al., 2005; Cox et al., 2017). These findings are corroborated by existing literature which found emotional aspects of EoLC were often heightened by close attachments with residents and relatives (Vandrevala et al., 2017). Few interventions focused on supporting the mental health and wellbeing of care home staff delivering EoLC.

Explicit detail on how those involved responded to interventions was largely absent. Despite all the interventions aiming to improve and support the EoLC experience for service users, few studies explored perceptions and interpretations of service users or their close others. This lack of insight is significant, given the increasing acceptance that EoLC should be everyone's business (RCP, 2015; RCP, 2016; Marie Curie, 2016), and that a wider range of people should be involved and given a voice in service provision and improvement (RCP, 2015). These finding are corroborated by a recent systematic literature review conducted by Greenwood et al. (2018), which explored the experiences of older people dying in care homes and found a dearth of qualitative research from the perspectives of those most closely involved in older people's death. Moreover, the lack of this perspective was particularly evident within residential care homes (Greenwood et al., 2018).

5.1 Future research

The review uncovered four main issues which require further research. Firstly, current evidence about the rationale behind intervention design, the effect of context, and the response of stakeholders to interventions is sparse. This means that the impact of these factors on outcomes has thus far not been adequately established. Consequently, research designed to uncover how these factors support or inhibit high quality EoLC, is needed in order to provide an adequate foundation for future interventions to support the more consistent delivery of high quality and sustainable EoLC in care homes.

Secondly, a lack of insight from residential homes was noted, with only six studies examining interventions in residential homes. Thus, the contextual differences between residential and nursing homes and their impact on EoLC is largely overlooked. Thus, more research in residential homes is needed in order to develop interventions based on the needs and issues of EoLC in that context.

Thirdly, most studies evaluated outcomes during or shortly after an intervention had concluded, meaning that the sustainability of outcomes from these interventions is unknown. Thus, more longitudinal research is required in order to determine sustainability, especially in relation to time-limited interventions.

Fourthly, 27 out of 41 studies included self-reported, subjective outcomes measures, which tended to produce more positive results than those studies which included objective outcome measures. There is therefore a need for a greater use of objective measures in the evaluation of outcomes.

Lastly, this review uncovered a number of overlooked perspectives which should be included in future research. These include incorporating the perspectives and viewpoints of non-registered care home staff, and those with non-formal caring roles, particularly within residential care homes. Additionally, as death changes the lives of significant others, it is recommended that the viewpoint of those closest to dying residents are included, as their viewpoint acts as a proxy for dying residents experiences.

5.2 Limitations

The strength of findings in this review are dependent upon the strengths of outcomes findings in the studies it reviewed, along with the comprehensiveness of their information about hypothesised intervention mechanisms, contextual mechanisms and human response. The weaknesses displayed by those studies in these areas are therefore reflected here. For example, care homes were often viewed as a singular context with little evidence about resident populations, funding structures or locations of the homes and how these factors influence how care is delivered and received.

The researcher recognizes that restricting the search to English language articles may mean some relevant papers may have been missed. In addition, a large proportion of included studies were conducted in the United Kingdom (n=26), which may limit the transferability of the findings and recommendations.

6 CONCLUSION

The most obvious conclusions from this review relate to the gaps in the current literature. In terms of outcomes, much of the current data is neither robust enough nor sufficiently longitudinal to draw conclusions out the effectiveness or sustainability of the interventions that have been developed. In terms of inputs, there is a paucity of information about the rationale behind the selection of active components in the interventions, about the most salient contextual factors affecting effectiveness, and of the responses to the interventions by stakeholding actors.

Nonetheless, the review does indicate some of the issues that are required to be dealt with in order to improve the effectiveness and sustainability of interventions designed to improve EoLC in care homes. It was consistently found that high staff turnover and the limited resources of care homes impacted on the sustainability and embedding of change into practice. Specifically, education delivery which was too demanding on resources and time, was often not sustained by care homes. However, these contextual barriers were generally only identified in studies evaluating outcomes over longer periods of time. Studies reporting on immediate outcomes following an intervention tended to report more positive outcomes.

In summation, if future interventions are to ensure effective and sustainable delivery of high quality EoLC across the care home sector, their design will need to be based on an explicit and evidence-based hypothicization of the change mechanisms they contain. They will also need to take into account the influence of contexts in the interventions will operate, and the attitudes and responses of those whom they will affect.

7 Relevance to clinical practice

While most of the evidence identified in this review was not strong, there was evidence to suggest that education and interprofessional collaboration can be an effective method for improving end of life care in care homes at least as long as the interventions are being applied. Evidence of the sustainability of beneficial effects on clinical practice following the cessation of time-limited interventions is very weak.

Author contributions:

Study design: AS, SP

Data extraction: AS, SP, JS, MB

Data analysis: AS, SP

Manuscript writing and revisions for important intellectual content: AS, SP, JS, MB

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