


ARTICLE

What socio-cultural, emotional and relational factors shape older people's experiences of death and dying in residential aged care? A scoping review

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Abstract

Research internationally has revealed a range of medical and health-related issues that shape care at the end of life for people living in residential aged care facilities (RACFs), their families and the staff who care for them. Yet, less is known about the lived experiences of residents, and the broader socio-cultural, emotional and relational factors that shape experiences of dying within such settings. In this article, we present findings from a scoping review designed to establish what is known about the lived experience of residents nearing the end of life. In doing so, we identify research gaps and move towards an agenda for future research. Five electronic databases were used to identify empirical research articles investigating end-of-life experiences from the perspective of older people living in RACFs, from which we selected 22 papers for thematic analysis. Our analysis highlighted three key themes: connections and closeness; place and the end of life; and temporality, care and the anticipation of dying. A majority of the articles (15) highlighted the importance of social connectedness with staff, co-residents and family in enabling people to die with dignity and a sense of belonging in residential settings. The physical layout and living arrangements in RACFs were found to affect the ways in which residents relate within the space, especially during and after the death of a resident. Anticipatory fears of dying were oriented towards the context of illness and care, and its management within the RACF, rather than death itself. Our analysis highlights considerable evidence that 'good deaths' are embedded in experiences of socio-emotional well-being, connectedness and relationality. However, much of the extant research analysed is exploratory, pointing to the need for further social scientific study of the social and cultural embeddedness of end-of-life experiences with residential aged care.

Keywords: residential aged care; death; dying; palliative care; end-of-life care; relationality; social connectedness; scoping review

Introduction

In high- and middle-income countries, populations are ageing rapidly, given improvements in life expectancy and falling fertility rates (Reher, 2015). The availability of life-prolonging medical treatments and technologies mean that dying in old age is often a protracted process, typically preceded by periods of frailty (Ellis *et al.*, 2016). A shift in policy in high-income countries over the last 20–30 years has seen an increasing emphasis (albeit sometimes not reflected in spending) on meeting care needs through the provision of services for older people in their own homes, decreasing admissions into residential aged care facilities¹ (RACFs) (Wanless, 2006; Penny, 2007; Khadka *et al.*, 2019). However, the consequence of this trend is that those who are admitted to residential aged care tend to be older, more frail and more unwell (Kristjanson, 2006). As such, RACFs are important sites of/for death and dying (Broad *et al.*, 2013).

In the last two decades, older people's end-of-life experiences in RACFs have become an area of particular attention for researchers and policy makers (Department of Health and Ageing, 2004; Abbey *et al.*, 2006; Allen *et al.*, 2008). Yet the parameters of scholarly and policy debate have been limited; hitherto, and as we aim to attend to in this review, the social, emotional and relational are largely understood *through* biomedical models and discourses. At the same time, older people's voices have been largely missing in discussions about how dying is experienced in residential aged care contexts (Davis-Berman, 2011; Djivre *et al.*, 2012; Fleming *et al.*, 2016; *see also* Millington-Sanders and Noble, 2018). Rather, residents' accounts have been subsumed within the burgeoning literature focused on clinical end-of-life care needs, family² and staff perspectives, and the structural constraints facing the aged care industry (Forbes-Thompson and Gessert, 2005; Munn and Zimmerman, 2006; Parker, 2011). This has led to calls for the accounts of residents themselves to be foregrounded in research on end-of-life experiences and care needs, particularly in terms of the meanings residents attribute to their own experiences (Froggatt *et al.*, 2006; Davis-Berman, 2011).

A small number of studies have shown that people living in residential aged care have distinct priorities and values that inform how they plan for, feel about and experience the dying process (Forbes-Thompson and Gessert, 2005; Ternstedt and Franklin, 2006; Dwyer *et al.*, 2008; Tan *et al.*, 2013; Sussman *et al.*, 2017). These studies add weight to the case for research that engages directly with older people within their context of care. In this paper, we present the results of a scoping review conducted to establish the available research on residents' experiences and perspectives on death and dying within residential aged care. In particular, we examined the literature on the socio-cultural, emotional and relational aspects of death and dying, to foreground lived experience of nearing the end of life in context and to complement the existing clinically-focused literature. Our findings suggest this is an under-researched area within the fields of social science, ageing and gerontology, and palliative and end-of-life care. We identify the need for a new research agenda centred around in-depth social science research that can illuminate the socio-cultural and relational factors shaping experiences of death and dying in residential aged care.

Despite the frequency of deaths in residential aged care, policies to inform practice on end-of-life care in these settings have only emerged in the last 20 years

internationally (National Health and Medical Research Council (NHMRC), 2006; Kinley *et al.*, 2013). While various national guidelines and standards have been in place for the provision of palliative care services, and for aged care services, these have been broadly considered as discrete spheres, without explicitly addressing care for the dying *within* aged care settings. In response, from the early 2000s, standards have been developed in many countries – at local and national levels – for improving palliative and end-of-life care integration into RACFs, including, for example, in the United Kingdom (UK), the Gold Standards Framework in Care Homes programme, the Integrated Care Pathway and the Daffodil Guidelines, and by 2010 the Route to Success programme designed to achieve quality in care homes (National Health Service, 2010) (*see e.g.* Froggatt *et al.*, 2006; Kinley *et al.*, 2013); in Australia, the Palliative Approach in Residential Aged Care (*see e.g.* NHMRC, 2006); and in the United States of America (USA), the National Consensus Project for Quality Palliative Care (American Academy of Hospice and Palliative Medicine *et al.*, 2004). More recently, interventions in various countries have aimed to better integrate palliative care into nursing homes (*see e.g.* the European PACE project: van den Block *et al.*, 2020; Honinx *et al.*, 2021).

Broadly speaking, such policy shifts have been grounded in recognition that to improve care for older people approaching the end of life in RACFs, there is a need to better understand their social, emotional, cultural and medical needs from the perspective of older people themselves. Yet palliative and end-of-life care within RACFs has tended to remain grounded in biomedicalised notions of the socio-cultural and relational, emphasising clinical needs and treatment, alongside the psycho-social (Banerjee and Rewegan, 2016). As such, approaches to care (in practice and research) is strongly focused on challenges identified by staff and professionals, rather than being grounded in older people's own preferences and experiences (Sussman *et al.*, 2017). Research evidence shows there are a number of barriers to the provision of more holistic end-of-life care in aged care settings, including a lack of co-ordination between aged care, primary care and hospital care (Unroe *et al.*, 2014; Cagle *et al.*, 2017), gaps in professional knowledge and skills in palliative care provision (Allen *et al.*, 2008), and inequities in access to palliative care services for elderly residents compared with people dying in a hospital or home settings (O'Connor and Pearson, 2004).

A growing corpus of research focuses on dying in RACFs as a 'process', recognising the dynamic, ongoing and changing character of dying and the provision of care therein, as experienced by a range of people, professionally or personally involved (*see e.g.* Cartwright, 2002; Parker Oliver *et al.*, 2005; Froggatt *et al.*, 2006; Fosse *et al.*, 2014). The majority of studies, spanning fields of nursing, medicine, gerontology and social work, have built an evidence base around the knowledge and production of practice, including professional understandings of palliative care principles, potential care and service provision improvements, and better understandings of the requirements and realities of professional expertise (*see e.g.* Carlson, 2007; Lee *et al.*, 2013; Livingston *et al.*, 2013). Much of this work emphasises ongoing assessment of the effectiveness and efficacy of care models and interventions (*see e.g.* Cartwright, 2002; Goodridge *et al.*, 2005; Phillips *et al.*, 2008; Waldrop and Kirkendall, 2009; Gonella *et al.*, 2019).

This and other literature has provided valuable insights into the obstacles and opportunities for aged care professionals as they navigate this complex area of care provision. However, critics have pointed to the problems of focusing on deficits rather than solutions, and of making assumptions about what ‘quality’ care means to older people (Froggatt *et al.*, 2006). Studies that aim to improve outcomes by quantifying and evaluating them against standardised ‘best practice’ models may fail to capture the holistic experience of death and dying in and across contexts (Greenwood *et al.*, 2018). Indeed, and as previous reviews have noted, there is a small but growing body of research on experiences of life close to death from the perspective of residents themselves (Froggatt *et al.*, 2006; Davis-Berman, 2011; Djivre *et al.*, 2012). This includes a number of meta-studies that foreground residents’ experiences and perspectives (Fosse *et al.*, 2014; Greenwood *et al.*, 2018; Wallace *et al.*, 2018). Yet, little is known about the socio-cultural and relational underpinnings of end-of-life experiences for aged care residents. In response, in this review our objective was to identify, synthesise and describe the findings of studies that explore the experiences of older people at the end of life in RACFs, with a focus on socio-cultural and relational experiences and needs.

Methodology

The purpose of this scoping review was to identify the social, emotional, relational and spiritual aspects of death and dying in residential aged care, and use this evidence to demonstrate the benefits of a socio-cultural and relational approach. A secondary aim was to identify gaps for more sociologically informed research in the future. A scoping review is a rigorous and structured method of identifying, synthesising and analysing published literature on a given topic (Bell *et al.*, 2017). Our approach is underpinned by Arksey and O’Malley’s (2005) scoping review framework, the aim of which is to ‘map *rapidly* the key concepts underpinning a research area and the main sources and types of evidence available’ (Mays *et al.*, cited in Arksey and O’Malley, 2005). The framework consists of five stages: (1) identifying the research question; (2) identifying relevant studies; (3) study selection; (4) charting the data; and (5) collating, summarising and reporting the results.

Stage 1: Identifying the research question

The scoping review aimed to answer the question: What is known about the social, emotional, relational and spiritual aspects of older people’s experiences of death and dying in RACFs?

Stage 2: Identifying relevant studies

We reviewed relevant research literature by searching databases and catalogues, and examining the reference lists of selected publications through forwards and backwards citation tracking. An initial set of search terms derived from the research question was used to conduct a limited, preliminary search of the literature, with the aim of identifying additional keywords and determining the scope of relevant literature. Five electronic databases (ProQuest, Scopus, SAGE, Web of Science

and JSTOR) were used to locate the articles analysed in this review. These are among the largest multi-disciplinary databases of peer-reviewed literature, selected to cover empirical research in fields of social work, nursing, sociology and social policy. In addition, Google Scholar and the catalogue of the University of New South Wales were used to optimise the results of the database searches and enhance the reliability of the search approach (Bramer *et al.*, 2017). The searches were conducted on 26 January 2023 and updated in July 2023 using the following combination of terms: 'dying' OR 'death' OR 'end-of-life' AND 'aged care' OR 'nursing home' OR 'residential care'. After reviewing the abstracts and keywords of the articles identified through the search, we subsequently added the additional search terms 'long-term care', 'experiences', 'expectations', 'perceptions' and 'attitudes', as well as 'covid', 'covid-19' and 'pandemic' to capture the impacts of COVID on older people's experiences.

The search parameters were limited to sources published between the years 2000 and early 2023, during which time research interest in end-of-life care in residential care settings increased rapidly following a number of major policy changes internationally. This period also allowed us to focus on contemporary residential aged care settings, which have been subject to widespread reform in many countries since the 1980s and 1990s (Allen *et al.*, 2008). The search produced a total of 17,858 titles; filters were applied to include only social science sources (per Scopus, SAGE, JSTOR and Web of Science filter) and sources in subject areas relevant to the research question (ProQuest). The resulting 1,713 articles were exported from the online databases into Endnote.

Stage 3: Study selection

Inclusion and exclusion criteria were developed and applied to the articles to determine whether they fit the purposes of the scoping review. An initial set of exclusion criteria were used to eliminate studies that did not relate to our central research question. Namely, studies focused on the clinical aspects of death and dying in aged care were excluded (*e.g.* medical interventions, pain management) so that only those papers related to socio-cultural, emotional and relational aspects remained in the sample. For the purposes of this review, socio-cultural factors refer to how individuals and communities perceive and encounter death and end-of-life care within their social and cultural contexts. This includes considerations such as religious beliefs, familial dynamics, social norms, cultural practices, and attitudes towards death and dying. Emotional aspects refer to the psychological and affective responses associated with death and dying, such as fear, anxiety, helplessness, boredom and coping mechanisms. Relational aspects encompass interpersonal dynamics, relationships and support systems that individuals and communities rely on as they approach the end-of-life, including family, friends and care-givers. Studies of death and dying in settings other than residential aged care were excluded, as were studies that did not directly engage with older people's experiences of death and dying (by including them and/or those close to them in the study sample). Also excluded from the review were publications in languages other than English, and non-scholarly publications such as newspapers and magazines, as well as unpublished manuscripts and conference papers.

Studies included in the scoping review comprised those with an empirical focus on the experiences of older people (aged 65 years and above) approaching the end of life in a nursing home, residential aged care or long-term care facility. Care models and terminology for care homes differ within and among the countries included in this review. Mindful of these differences, our search approach used variations of country-specific terminology (*e.g.* nursing home, long-term care, *etc.*), while in the article we use the term residential aged care facility (RACF).

The ethical and practical challenges of undertaking research with older people and/or those facing death in aged care settings clearly limits opportunities for older people's participation in research. We therefore sought to identify and synthesise research that also described the experiences of these older people as perceived by their families and staff working closely with them. That is, studies that focus on aged care workers and families or informal care-givers (relations and friends) with direct involvement in the dying experience of an older resident, and which focus on the experiences of the older resident, were also included *provided the study sample included older people*. Geographical parameters were also applied, such that only studies conducted within Organisation for Economic Co-operation and Development countries with broadly comparable aged care systems (*i.e.* those that are partly or entirely publicly subsidised to enable access to paid care for some or all of the population) were included. Only journal articles and other scholarly outputs (*i.e.* book chapters, books) were chosen for inclusion in the review. Sources that did not conform to these criteria were excluded based on an initial reading of the title and then abstract. The articles were then read in full to determine whether each should be chosen for inclusion in the review. This yielded a corpus of 16 scholarly research articles. An additional six sources were located by reviewing the reference list of selected publications, such as existing literature reviews, and tracing these citations. The complete selection process is depicted in [Figure 1](#). We used the PRISMA scoping review extension checklist for reporting (Tricco *et al.*, 2018). According to Arksey and O'Malley (2005), scoping reviews do not usually include quality assessment tools. Nevertheless, we used the Critical Appraisal Skills Programme (CASP, 2018) qualitative checklist to evaluate the studies. GVT and EK independently assessed each study's methodological quality against the criteria listed in the CASP, and were deemed of suitable quality. In addition, the authors discussed the quality of each study as part of our interpretation and analysis.

We note the limitations of our process: literature may be missed due to selection of databases (other databases may have elicited additional results), exclusion of grey literature, and exclusion of articles published in languages other than English. Given the thematic focus of our analysis, we also cannot make claims regarding gaps in the literature related to study quality.

Stage 4: Charting the data

Each paper in the final list of 22 references was then 'charted' according to key issues/themes/approach (Arksey and O'Malley, 2005; Levac *et al.*, 2010). Guided by Arksey and O'Malley's (2005) descriptive-analytical method, we applied a common analytical framework to each research article and extracted key contextual and

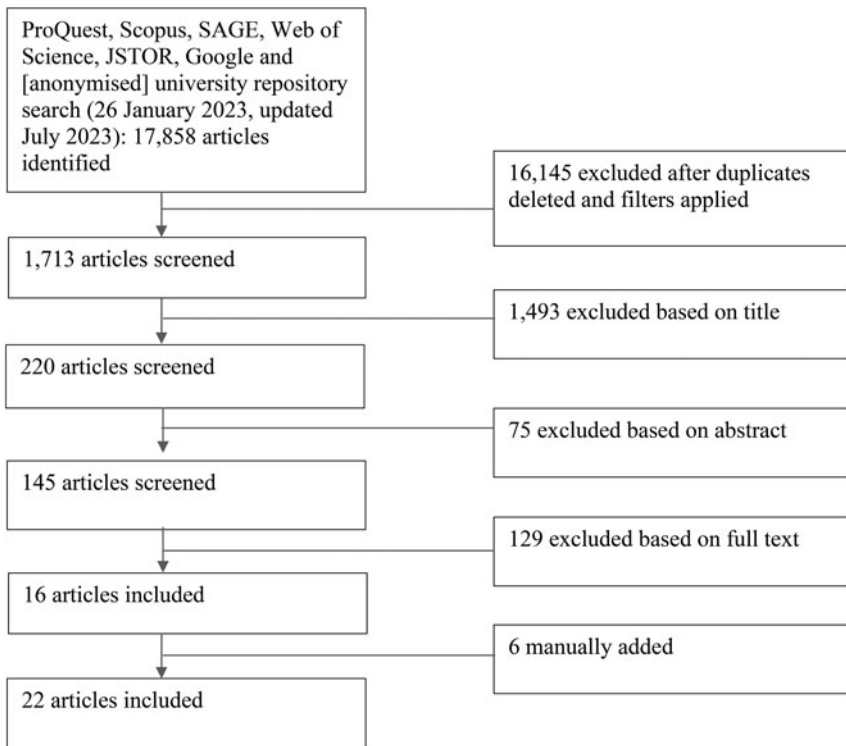


Figure 1. Flow chart of the selection process.

methodological information on each study (author/s, title and year of publication, country in which the study was conducted, aims of the study and methodological approach). The data that we charted were entered into a Word-based data charting form, depicted in Table 1.

Stage 5: Collating, summarising and reporting the results

The results of the charting exercise were collated; then we undertook a process of reflexive thematic analysis, following Braun and Clarke (2006, 2019, 2021). This involved the authors each familiarising ourselves with the data by reading each study article. Then GVT and EK generated initial codes and themes, before the authors collectively and iteratively refined the themes through regular discussion and review meetings. Our coding processes, including the generation and refinement of themes, involved the authors interpreting the findings of each study, querying and questioning our assumptions about the data, and then working collaboratively to develop themes as analytic outputs. Following Braun and Clarke (2019), we foregrounded reflective and thoughtful engagement with data and with the analytic process, to develop reflexively our reading of the data, and our resultant themes. The findings of this analysis are reported below, in an analytical summary of the key themes identified in the 22 articles. Our analysis

Table 1. Characteristics of the included studies

Author/s	Title	Year	Country	Research question/ aim	Method	Participants sampled
Dwyer <i>et al.</i>	Three nursing home residents speak about meaning at the end of life	2008	Sweden	Acquire a deeper understanding of how three older women create meaning in their everyday life in a nursing home	Interviews, inductive hermeneutic approach	3 elderly residents
Franklin <i>et al.</i>	Views on dignity of elderly nursing home residents	2006	Sweden	Explore the views on dignity at the end of life of 12 elderly people living in two nursing homes in Sweden	Semi-structured interviews, hermeneutic approach	12 elderly residents
Österlind <i>et al.</i>	Feeling lonely in an unfamiliar place: older people's experiences of life close to death in a nursing home	2017	Sweden	Deepen the understanding of how older persons living in a nursing home experience life close to death	Qualitative interviews, interpretive approach	6 elderly residents
Ternstedt and Franklin	Ways of relating to death: views of older people resident in nursing homes	2006	Sweden	Reach a deeper understanding of seven older people's thoughts, feelings and attitudes towards death	Qualitative, hermeneutic approach; interviews	7 elderly residents
Tishelman <i>et al.</i>	Beyond the visual and verbal: using participant-produced photographs in research	2016	Sweden	Better understand which aspects of residents' surroundings are particularly	Participant-produced photographs with subsequent interviews	23 people approaching end of life in in-patient palliative care/hospice units,

	on the surroundings for care at the end-of-life			meaningful for the people inhabiting them in the last phases of life		specialised palliative care home care and residential care facilities for the elderly
Whitaker	The body as existential midpoint – the aging and dying body of nursing home residents	2010	Sweden	Explore nursing home residents' experiences of their ageing and dying bodies by focusing on the link between the body, ageing and death in an institution-based eldercare context	Ethnography; informal conversations, reflexive interpretation	Nursing home residents, family members and staff
Tjernberg and Bökberg	Older persons' thoughts about death and dying and their experiences of care in end-of-life: a qualitative study	2020	Sweden	To explore thoughts about death and dying and experiences of care at end of life among older persons living in nursing homes	Interviews, content analysis	36 older residents
Fleming <i>et al.</i>	Death and the oldest old: attitudes and preferences for end-of-life care – qualitative research within a population-based cohort study	2016	UK	Understand very old people's preferences regarding care towards the end of life and attitudes towards dying, to inform policy and practice	Interviews, mixed-methods population-based cohort study	42 people aged 95–101
Mathie <i>et al.</i>	An uncertain future: the unchanging views of care home residents about living and dying	2012	UK	Explore the views, experiences and expectations of end-of-life care	Prospective design, qualitative interviews	63 care home residents

(Continued)

Table 1. (Continued.)

Author/s	Title	Year	Country	Research question/ aim	Method	Participants sampled
				among care home residents to understand if key events or living in a residential environment influenced their views		
Stone	Understanding consumption within a care home: an interpretation of George's experiences of life and death	2009	UK	How do elderly consumers make sense of their lived experiences within care homes?	Existential-phenomenology approach, exploratory interviews	1 elderly care home resident
Goodman <i>et al.</i>	Preferences and priorities for ongoing and end-of-life care: a qualitative study of older people with dementia resident in care homes	2013	UK	Explore how older people with dementia discuss their priorities and preferences for end-of-life care	Exploratory, qualitative design using 'guided conversations'	18 people with dementia, living in a care home
Kayser-Jones	The experience of dying: an ethnographic nursing home study	2002	USA	Investigate the process of providing end-of-life care to residents who were dying in nursing homes	Participant observation, in-depth interviews and event analysis	Nursing home residents (N = 35), their families (N = 52), nursing staff (N = 66) and physicians (N = 36)
Munn <i>et al.</i>	The end-of-life experience in long-term care: five themes identified from focus	2008	USA	Examine the end-of-life experience in long-term care	Focus groups, grounded theory approach	Long-term care residents, family care-givers, paraprofessional

	groups with residents, family members, and staff			based on input from key stakeholders		staff and licensed/registered staff
Davis-Berman	Conversations about death: talking to residents in independent, assisted, and long-term care settings	2011	USA	Allow respondents to tell their own stories and discuss ideas, concerns and beliefs about death	Semi-structured interviews, inductive narrative approach	17 older residents
Parker <i>et al.</i>	A palliative approach or specialist palliative care? What happens in aged care facilities for residents with a noncancer diagnosis?	2005	Australia	Explore the palliative care needs of 69 residents with a non-cancer diagnosis in South Australia	Mixed methods; survey, case notes and interviews	Older residents and staff
Parker	Residential aged care facilities: places for living and dying	2011	Australia	Identify how the use of space within residential aged care affects residents' identity, and on the nature of death scenes within RACFs	Ethnography, participant observation	11 residents, their family and staff
Wardle and Bennett	Spiritual inclusiveness at end-of-life for Punjabi Indians: experience with Regional Residential Aged Care Facilities	2021	Australia	Identify and explore the psychosocial, religious and spiritual end-of-life care needs of the older Punjabi Indians during the end-of-life trajectory at RACFs	Interpretive phenomenological approach; in-depth semi-structured group interviews	Older residents and staff
Sussman <i>et al.</i>	Broadening end-of-life comfort to improve palliative care practices in long term care	2017	Canada	How do staff, residents and families currently understand and	Qualitative, grounded theory approach, focus groups	Elderly residents, family members and staff

(Continued)

Table 1. (Continued.)

Author/s	Title	Year	Country	Research question/ aim	Method	Participants sampled
				experience palliative care in long-term care? How might current understandings and experiences of palliative care be adapted to address the needs of all residents living and dying in long-term care, and those of the families and staff who support them?		
Djivre <i>et al.</i>	Five residents speak: the meaning of living with dying in a long-term care home	2012	Canada	Further understand the experiential qualities of being a resident who must live with dying	Semi-structured interviews, hermeneutic phenomenological approach	Elderly residents
Pleschberger	Dignity and the challenge of dying in nursing homes: the residents' view	2007	Germany	Explore the meaning of dignity with regard to end-of-life issues from the perspective of older nursing home residents in western Germany	Grounded theory approach; narrative interviews	Elderly residents
Gjerberg <i>et al.</i>	End-of-life care communications and shared decision-making in Norwegian nursing homes – experiences and	2015	Norway	Explore nursing home patients' and next-of-kin's experiences with and perspectives on	Qualitative and explorative design, individual interviews and focus groups	33 elderly residents and 35 relatives

	perspectives of patients and relatives			end-of-life care conversations, information and shared decision-making		
Frey and Balmer	Resident and family spirituality in New Zealand residential aged care: an exploration	2022	Aotearoa/ New Zealand	Explore the constituents of spirituality for six residential aged care residents and six bereaved family members	Qualitative descriptive design; semi-structured interviews	6 residential aged care residents and 6 bereaved family members

Notes: UK: United Kingdom. USA: United States of America. RACFs: residential aged care facilities.

highlighted three main themes related to the social, emotional, relational and spiritual dimensions of death and dying in aged care: connections and closeness; place and the end of life; and temporality, care and the anticipation of death.

Findings

Sample characteristics and summary

All 22 papers incorporated older people in their study sample, while nine of them also drew on data collected through interviews and focus groups with family members and staff. The final collection comprised seven papers from Sweden, four from the UK, three from the USA, three from Australia, two from Canada, and one from Germany, Norway and Aotearoa/New Zealand, respectively (see Table 1). All the studies adopted a qualitative approach, incorporating in-depth interviews, focus groups, surveys and/or participant observation.

Despite cultural, geographic and care system differences, there were shared perspectives among older people across these countries, particularly regarding the social-relational aspects of ageing and end-of-life care. A majority of the articles (14) identified social connectedness as central to older people's experiences of living and dying well in residential settings (Kayser-Jones, 2002; Franklin *et al.*, 2006; Ternstedt and Franklin, 2006; Pleschberger, 2007; Dwyer *et al.*, 2008; Munn *et al.*, 2008; Parker, 2011; Djivre *et al.*, 2012; Goodman *et al.*, 2013; Fleming *et al.*, 2016; Österlind *et al.*, 2017; Sussman *et al.*, 2017; Tjernberg and Bökberg, 2020; Frey and Balmer, 2022). As they approached the end of their life, older people's feeling of being cared for and cared about was closely linked to the significance of their relationships and interactions with both other residents and staff (Kayser-Jones, 2002; Dwyer *et al.*, 2008; Munn *et al.*, 2008; Parker, 2011; Djivre *et al.*, 2012; Goodman *et al.*, 2013; Fleming *et al.*, 2016; Sussman *et al.*, 2017). Across the range of countries studied, the research consistently recognised common themes concerning the socio-emotional dimensions of end of life care. These themes included comfort (Sussman *et al.*, 2017), dignity (Kayser-Jones, 2002; Franklin *et al.*, 2006; Pleschberger, 2007), clear and open communication (Kayser-Jones, 2002; Gjerberg *et al.*, 2015; Sussman *et al.*, 2017) and close, trusting relationships (Munn *et al.*, 2008; Goodman *et al.*, 2013). The quality of relationships with staff were seen to indicate whether residents' preferences for the end of life would be respected (Goodman *et al.*, 2013). Other studies highlighted that having connections with family and friends provides individuals with a sense of meaning and belonging, and in the absence of such connections, there may be a decrease in motivation to continue living (Ternstedt and Franklin, 2006; Dwyer *et al.*, 2008; Goodman *et al.*, 2013; Österlind *et al.*, 2017).

Connections and closeness: relational support

Our review found that while social connectedness is important to dying well in RACFs, it is not always available to residents nearing the end of life. The articles highlighted a range of barriers to the formation and maintenance of meaningful social relationships, which older people encountered in various residential settings.

These included a sense of detachment from others despite co-habitation (Djivre *et al.*, 2012), feelings of abandonment and neglect due to the absence of family and the time poverty of staff (Franklin *et al.*, 2006; Dwyer *et al.*, 2008; Sussman *et al.*, 2017), and assumptions, made by staff, that residents would prefer to avoid communal spaces in the last days and weeks of life (Parker, 2011). Experiences of loneliness linked to the absence of family and friends and other forms of relational support, such as connectedness with staff, left residents with feelings of isolation, socio-cultural dislocation and lack of belonging at the end of life (Kayser-Jones, 2002; Franklin *et al.*, 2006; Ternestedt and Franklin, 2006; Österlind *et al.*, 2017). For residents in the Swedish study of Dwyer *et al.* (2008), connection with family was a means by which residents could locate themselves relationally in the world beyond the RACF (e.g. as a wife, mother and grandmother), giving meaning and purpose to their life within it. Family provided a context in which the dying person is 'seen', 'needed' and 'known' in an environment that might otherwise be experienced as impersonal and alienating (Ternestedt and Franklin, 2006; Tjernberg and Bökberg, 2020).

Residents who lacked emotional intimacy and meaningful connections in their lives in some cases saw death as bringing relief from feelings of 'existential homelessness' (Österlind *et al.*, 2017: 7). Isolation was also linked to aspects of ageing such as the loss of vital bodily functions and autonomy. The shame associated with ageing can invoke feelings of dependency, burden and lack of belonging, negatively affecting one's self-image and relations with others, particularly in societies such as the Nordic countries where formal obligations or strong norms for the family to care for older parents are less strongly culturally prescribed, and in liberal democracies that prioritise individualism and independence over collective responsibility and support for older people (Pleschberger, 2007; Dwyer *et al.*, 2008; Fleming *et al.*, 2016; Österlind *et al.*, 2017; Tjernberg and Bökberg, 2020). Bodily deterioration and decreasing independence prompted feelings of shame and embarrassment among some residents in the Swedish study of Franklin *et al.* (2006), compelling them to withdraw from social relationships and activities. In this sense, isolation was utilised by some older people as a means of preserving dignity and enacting control over one's life as the body declines and the end of life nears. While older people at the end of life need access to privacy and autonomy, isolation from social contact due to embarrassment is deeply damaging to dignity and inhibits these residents' enjoyment of the value that social relationships bring at the end of life.

Openly discussing one's own death and the deaths of others was found to be particularly crucial for allaying fears, gaining knowledge and preserving emotional intimacy in times of uncertainty and distress, highlighting the significance of connection (Kayser-Jones, 2002; Djivre *et al.*, 2012; Gjerberg *et al.*, 2015; Sussman *et al.*, 2017; Tjernberg and Bökberg, 2020). The importance of strong family connections was expressed in the desire to have sufficient time to say a final goodbye, as well as the wish to be emotionally and mentally prepared for death when it eventually arrives (Tjernberg and Bökberg, 2020). In multicultural countries with substantial immigrant populations, such as Australia, Canada, the UK and the USA, the significance of spiritual support at the end of life was perceived variously among individuals with religious beliefs. Among some older people, including the Punjabi Indian residents interviewed in Wardle and Bennett's (2021)

Australian study, there was disappointment that such services were exclusively provided from a Christian perspective. For them, the presence of pastoral care providers was considered important in establishing a nurturing spiritual environment during the dying process.

Place and the end of life

Djivre *et al.* (2012), following Froggatt (2001), note that the experience of living and dying in the same space is an essential feature of life in aged care homes. The space contains an ‘inherent cultural ambiguity’ of simultaneously being a home, a site of institutional care and a place of death for residents (Whitaker, 2010: 102). RACFs were recognised in all the reviewed articles as both a place of care and a place of dying and death. Despite geographical and cultural distinctions, there were a number of commonalities related to institutionalised, communal living and the implications therein for how residents experience death and dying (both their own dying process and the deaths of other residents) (Dwyer *et al.*, 2008; Davis-Berman, 2011; Parker, 2011; Djivre *et al.*, 2012; Goodman *et al.*, 2013). Several of the articles noted that living in a RACF meant living in ongoing proximity to dying and death – death was a frequent occurrence and was to some degree normalised within that space (Munn *et al.*, 2008; Whitaker, 2010; Djivre *et al.*, 2012; Sussman *et al.*, 2017). Residents had shared experiences of other residents’ death, which at times prompted thought and discussion around dying (Davis-Berman, 2011). Talking about and working towards acceptance of death was a collective endeavour in which residents felt ‘a sense of community where everyone was “in it” together’ (Djivre *et al.*, 2012: 502).

Living in a place of care meant that residents’ lives were often dictated by the norms, values and routines of the institution (Djivre *et al.*, 2012; Österlind *et al.*, 2017). In their study of older people’s experiences of life close to death in a Swedish aged care home, Österlind *et al.* (2017) found that residents perceived their physical and existential living space as ‘shrinking’ as a result of their subordination to institutional processes and imperatives. Several studies noted that dying in aged care entails a lack of choice about the location and management of death (Pleschberger, 2007; Whitaker, 2010; Mathie *et al.*, 2012; Sussman *et al.*, 2017). Some residents were not aware of or concerned about end-of-life choices; others were offered choice but this was confined to the range of options available within the institution, when their preference was to die at home or be closer to relatives (Mathie *et al.*, 2012). Residents reported a desire for ‘quality’ care at the end of life, by which they meant care that attends to both the corporeal and their social, emotional and spiritual needs, such as the need for connection, support, comfort, personal regard, compassion, and opportunities for spiritual or religious expression (Franklin *et al.*, 2006; Whitaker, 2010; Djivre *et al.*, 2012; Sussman *et al.*, 2017; Wardle and Bennett, 2021; Frey and Balmer, 2022). For the Punjabi Indian participants in Wardle and Bennett’s (2021) Australian study, spiritual-religious services were considered vital for people at the end of life, providing opportunities for communal worship and the performance of important death-related rituals. That institutional structures meant these services were often inaccessible to individuals and families at the end of life was a cause of great anguish. Frey and Balmer (2022)

and Wardle and Bennett (2021) highlight the importance of spiritual care and opportunities for religious expression, noting that people's fear of death is heightened when their specific religious and cultural needs are not well understood or incorporated into their care.

Resourcing and staffing constraints were identified in a number of studies as a major impediment to the delivery of quality, relationally focused end-of-life care (Kayser-Jones, 2002; Munn *et al.*, 2008; Djivre *et al.*, 2012). Parker (2011), for example, notes that the management of death in Australian aged care facilities is geared to meeting economic and biomedical outcomes, rather than social and personal ones, despite their apparent incorporation of the discourse of dying/palliative care. Residents in the study by Djivre *et al.* (2012: 509) expressed fear, helplessness and anger at the depersonalisation of care at the end of life, which they viewed as a by-product of the commodification of care resulting from recent health-care reforms in Canada.

Temporality, care and the anticipation of the end of life

Approximately half of the studies identified that the passing of time, reflecting on the past and looking to the future, and the time-delimited experience of living in a RACF, were important aspects of the experiences of older people in residential aged care that shaped their understanding of death and dying (Franklin *et al.*, 2006; Ternstedt and Franklin, 2006; Whitaker, 2010; Davis-Berman, 2011; Djivre *et al.*, 2012; Mathie *et al.*, 2012; Gjerberg *et al.*, 2015; Fleming *et al.*, 2016; Österlind *et al.*, 2017; Sussman *et al.*, 2017). While time as a concept was often not explicit, the concerns raised by older people facing the end of life in RACFs often contained a temporal orientation. Most commonly, time was evident in the different possibilities, projected by older people, of what might happen in the days, weeks and years leading up to the end of life. Residents identified concern about the potential for progressive deterioration, including the development of illness, disease and pain (Whitaker, 2010), fear of losing control and being increasingly dependent on others (Franklin *et al.*, 2006; Ternstedt and Franklin, 2006; Davis-Berman, 2011) and anxiety about the adequacy of the end-of-life care they would receive within the RACF (Djivre *et al.*, 2012). Some described themselves as 'resigned' to and 'prepared' for death (Mathie *et al.*, 2012: 738), which was to be 'expected' in old age (Österlind *et al.*, 2017: 4). Others expressed a wish to die out of a sense of sadness, weariness, frustration or purposelessness which made it 'very difficult just sitting there waiting to die' (Goodman *et al.*, 2013; Fleming *et al.*, 2016; Österlind *et al.*, 2017: 4). For these residents the future felt 'limited ... now they were in a care home'; a way to cope was to not think about the future and instead live life day by day (Mathie *et al.*, 2012: 738).

Our review found that older people were primarily concerned with anticipating the process of dying and its management within the RACF, rather than the concept or moment of death itself. These concerns often centred on the social, emotional, cultural and spiritual aspects of end-of-life care, the constraints on staff investment in *time*, and the ways in which this created greater fear in the anticipation of dying. The most widespread concern reported across the articles was the fear of becoming dependent on others and the associated loss of autonomy, dignity and control over

one's life and body (Franklin *et al.*, 2006; Pleschberger, 2007; Dwyer *et al.*, 2008; Whitaker, 2010; Davis-Berman, 2011; Mathie *et al.*, 2012). A complex interplay of emotions underpinned these anxieties about dying in residential aged care. A resident in Ternstedt and Franklin's (2006) Swedish study described her frustration at not being able to 'influence anything'; having previously lived an independent life, she felt disempowered by the staff not 'pay[ing] any attention to what I say' and the clinical notions of care that prevailed in her residential environment. A resident in the study of Dwyer *et al.* (2008: 102) described her life in a Swedish nursing home as a 'non-life' because 'no one has time for us ... if only there was warmth and dignity in this care then maybe it could be called care, but there is no warmth or dignity'. In studies across various countries, feelings of helplessness and incapacitation were linked to both bodily alienation and loss of identity (*e.g.* Whitaker, 2010: 103). The loss of certain bodily functions led to an inevitable dependency, but it was the management of that dependency that was most important for older people's self-image and identity as they anticipated their future selves (Franklin *et al.*, 2006: 138). These emotional anxieties around care were heightened by the anticipation of death, and in some cases instilled in people a wish to die (Dwyer *et al.*, 2008; Whitaker, 2010; Fleming *et al.*, 2016; Österlind *et al.*, 2017). Others described feeling helpless and angry about the depersonalised care they witnessed others receiving and believed they too would experience at the end of life (Djivre *et al.*, 2012).

Discussion

Our findings allow us to conceptualise RACFs as social worlds, comprising residents, families and a range of staff, including visiting health-care and allied health professionals. Everyday life in these facilities is profoundly shaped by the relationships within and between these groups of actors. Yet, the role of relationships in the provision and receipt of end-of-life care in these settings remains under-examined and under-theorised. Most of the small number of papers in this area are descriptive and exploratory. There are notable gaps in understandings of the socio-relational experiences and needs at the end of life among marginalised groups of care recipients such as people from culturally and linguistically diverse backgrounds (Johnstone *et al.*, 2018), older LGBTQ+ adults (Almack *et al.*, 2010) and younger people in residential aged care (*e.g.* people with disability, stroke victims and those with early onset dementia) (Hussain *et al.*, 2019). These groups are likely to face greater challenges with respect to the relational and cultural ties that foster meaningful lives and deaths within aged care contexts (Almack *et al.*, 2010; Johnstone *et al.*, 2016; Kortés-Miller *et al.*, 2018). It is thus crucial that, when engaging with or even moving beyond the biomedical paradigm, research prioritises the need to better understand the social and relational experiences of life close to death for diverse groups of older people.

Conceptualising *good* care, and *good* deaths, requires consideration of relationality, socially mediated belief systems, ideals and expectations that vary within and across cultures (Chan and Kayser-Jones, 2005). For example, the literature we reviewed suggests that, for older people in societies with a liberal ethos emphasising individual agency and empowerment, a good death is fundamentally linked to dignity and choice at the end of life. However, what is meant by 'dignity' or 'choice' in

the context of RACF literature remains under-explored and interrogated, in particular how they are understood and enacted relationally. This review has helped to demonstrate that dignity is embedded in everyday social interactions and a broader socio-cultural milieu in which death and dying and ageing bodies are discussed and dealt with openly and free of stigma. At the same time, perceptions and experiences of choice and autonomy are enmeshed in opportunities for connection with family and establishing meaningful relationships with staff. Nonetheless, the latter aspect becomes increasingly challenging in countries such as Canada, Australia, the UK and the USA, where aged care systems are notably shaped by resource rationing and cost-minimisation imperatives, limiting the ability of staff to dedicate time and resources to nurturing these vital connections with residents (Kayser-Jones, 2002; Parker, 2011; Sussman *et al.*, 2017). There was sufficient evidence to suggest that social isolation at the end of life can limit dignity and choice and can prompt residents to avoid confronting the possibility of death, or even to report wanting death to come sooner. Our analysis also identified how residents' conceptions of the present and future were at times dominated by the anticipation of death, and that the socio-emotional characteristics of death and dying in the institution in which they lived – more than the clinical care and treatment – can play a strong role in whether they anticipated dying and death with fear or acceptance.

Since 2020 there have been huge impacts and changes within residential aged care worldwide as a result of the COVID-19 pandemic. In many of the countries included in this review, significant numbers of people have died in long-term care, where COVID outbreaks within aged care settings have profoundly affected older people, with high risk of infection and mortality (Hack *et al.*, 2022; Leontowitsch *et al.*, 2023). While our searches yielded only very limited literature on the topic of this scoping review in relation to COVID, various literature has pointed to the importance of sustained attention on the social dimensions of end-of-life experiences in residential aged care settings. Analyses of staff and family accounts, for example, have highlighted the additional challenges to *dying well* amidst the conditions imposed by COVID, *e.g.* safety measures and containments, and the consequences of enforced isolation and restrictions on visitors for social connection and quality of care (*e.g.* Parks and Howard, 2021; Hack *et al.*, 2022). Indeed, the pandemic has prompted a heightened awareness of anticipated death, with potential to profoundly refocus care within RACFs towards issues related to the end of life, including the alleviation of suffering, dignity and compassion. So too have social and relational 'needs' been identified as critical to forms of care amidst COVID (as well as in 'usual' care). Relationships are important in the recognition of palliative care needs and day-to-day experiences of living (and dying) in RACFs (Molloy and Phelan, 2022). Relational experiences, such as experiences of 'saying goodbye' to family (Hanna *et al.*, 2021), and respect and agency in advanced care planning processes, increasingly recognise the needs of residents as they navigate the experiences of the last weeks of life. Moreover, the pandemic has heightened awareness of the social and relational aspects of the end of life in the experiences, communicative strategies and health outcomes of bereaved relatives (*e.g.* Feder *et al.*, 2021). Research is beginning to reveal the ways that COVID may have accelerated policy and practice that foregrounds palliative and end-of-life care as core business for RACFs, *e.g.* through regular staff palliative care training (Hack *et al.*, 2022). But there is still much to be

understood in terms of the ways COVID experiences have shaped how RACFs attend to the social and relational aspects of the end of life.

Conclusion

Above, we have highlighted some of the conceptual and empirical poverty in approaches to identifying the socio-cultural and relational needs of RACF residents nearing the end of life. This present lack of socially and relationally attuned end-of-life care analysis of RACFs, we argue, has implications for the wellbeing of older residents in both their everyday lives and their sense of the future. This is likely due to policy settings and institutional structures, present to varying degrees in all the countries included in this review, which limit opportunities for socially and relationally focused care. The time available by residential aged care staff to invest in relationships, cultivate open communication with and between residents, and support residents to build social and cultural connection within and outside the facility is highly restricted in contexts of limited funding, understaffing and poor remuneration (Baines *et al.*, 2022). The opportunities for residents to exercise choice and to experience dignity at the end of life – both deeply relationally embedded – are also institutionally constrained by limited resources and a regulatory context that does not place value on time spent investing in relationships. We also found that those very relationships can mediate the experience of and confidence in clinical care at the end of life. Thus, rather than being two separate spheres of end of life care, social and relationally focused care and clinical practice are deeply intertwined in the experiences of older people at the end of life. More work is needed to explore relationality in modes of clinical practice at the end of life, and the implications for the experiences of older people in RACFs. These challenges in the policy and sectoral contexts are increasingly important amidst current trends facing the residential aged care industry, such as more complex care profiles of residents, workforce shortages, stubbornly under-recognised and poorly remunerated workforces, the persistent impacts of the COVID-19 pandemic, and growing scrutiny and accountability related to abuse and mistreatment. Elevating the voices of older people living (and dying) within aged care facilities is a vital part of reshaping care provision to improve everyday experiences.

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Ethical standards. Ethical approval was not required for this study.

Notes

1 Within and across middle- and high-income countries, care facilities for older people include nursing homes, independent or assisted living settings, or long-term care facilities. Notwithstanding variation in the levels of care provided across these settings, hereon we refer collectively to such settings as residential aged care facilities (RACFs), as sites where older people who require assistance with daily living activities and medical care reside 24/7 in a specialised facility with the on-site presence of physicians, specialists, nursing staff and nursing aids.

2 It is not straightforward to label the people who surround an older person: they may or may not be *kin*, *significant others*, *loved ones* and so on, nor do these terms necessitate relational meaning or importance. To streamline here, we refer to those ‘personal communities’ (Pahl and Spencer, 2004) who form samples within the reviewed research studies (variously termed) as *family*.

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