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

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 wellbeing, 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, Winslow and Noble 2016). A shift in policy in high-income countries over the last 20 to 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 facilities (Khadka *et al.* 2019; Penny 2007; Wanless 2006). 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, residential aged care facilities¹ (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 (Abbey *et al.* 2006; Allen *et al.* 2008; Department of Health and Ageing 2004). Yet the parameters of scholarly and policy debate have

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 terms/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 onsite presence of physicians, specialists, nursing staff and nursing aids.

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 (Fleming *et al.* 2016; Davis-Berman 2011; Djivre *et al.* 2012; 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 (Parker 2011; Munn and Zimmerman 2006; Forbes-Thompson and Gessert 2005). 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; Dwyer, Nordenfelt and Ternstedt 2008; Ternstedt and Franklin, 2006; 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 the 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

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 & Spencer, 2004) who form samples within the reviewed research studies (variously termed) as *family*.

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 (Kinley, Froggatt and Bennett 2013; NHMRC 2006). 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 residential aged care facilities, including for example: in the United Kingdom, the Gold Standards Framework in Care Homes programme, the Integrated Care Pathway, and the Daffodil Guidelines, and by 2010 the Route to Success program designed to achieve quality in care homes (NHS National End of Life Care Programme, 2010) (see for example Froggatt *et al.* 2006; Kinley *et al.* 2013); in Australia, the Palliative Approach in Residential Aged Care (see for example; NHMRC 2006); in the United States, the National Consensus Project for Quality Palliative Care (American Academy of Hospice and Palliative Medicine, 2004). More recently, interventions in various countries have aimed to better integrate palliative care into nursing homes (see for example the European PACE project: Honinx *et al.*, 2021; van den Block *et al.*, 2020).

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 coordination between aged care, primary care and hospital care (Cagle *et al.* 2017; Unroe *et al.* 2014), 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, for example, Parker Oliver *et al.* 2005; Fosse *et al.* 2014; Froggatt *et al.* 2006; Cartwright 2002). 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, for example, 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, for example, Gonella *et al.* 2019; Cartwright 2002; Waldrop and Kirkendall 2009; Goodridge *et al.*, 2005; Phillips *et al.* 2008).

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, Adorno and Stewart 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, Roberts and Popay

2001: 194, 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; (5) collating, summarizing 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 residential aged care facilities?

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 multidisciplinary 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 1713 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 caregivers. 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 caregivers (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 OECD 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 17 scholarly research articles. An additional five 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 & 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. Authors A and B 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 the grey literature, 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.

[Figure 1 here]

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 descriptive-analytical method (2005), we applied a common analytical framework to each research article and extracted key contextual and 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 results: The results of the charting exercise were collated; then we undertook a process of reflexive thematic analysis, following Braun & Clarke (2006; 2019; 2021). This involved the authors each familiarising ourselves with the data by reading each study article. Then Authors A and B 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 & Clarke (2019), we foregrounded reflective and thoughtful engagement with data and with the analytic process, to reflexively develop 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 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.

[Table 1 here]

Findings

Sample Characteristics and Summary

All 22 papers incorporated older people in their study sample, while 9 of them also drew on data collected through interviews and focus groups with family members and staff. The final collection comprised 6 papers from Sweden, 3 from the United States, 4 from the United Kingdom, 3 from Australia, 2 from Canada, and 1 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 aging and end-of-life care. A majority of the articles (fifteen) identified social connectedness as central to older people's experiences of living and dying well in residential settings (Österlind et al. 2017; Franklin, Ternestedt and Nordenfelt 2006; Dwyer, Nordenfelt and Ternestedt 2008; Ternestedt and Franklin 2006; Fleming et al. 2016; Parker 2011; Djivre *et al.* 2012; Österlind et al. 2017; Goodman et al. 2013; Kayser-Jones 2002; Sussman et al. 2017; Munn *et al.* 2008; Pleschberger 2007; Frey and Balmer 2022; Tjernberg and Bökberg 2020). 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 (Dwyer, Nordenfelt and Ternestedt 2008; Goodman et al. 2013; Kayser-Jones 2002; Parker 2011; Sussman et al. 2017; Munn et al. 2008; Djivre et al. 2012; Fleming et al. 2016). 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 (Pleschberger 2007; Kayser-Jones 2002; Franklin, Ternestedt and Nordenfelt 2006), clear and open communication (Gjerberg et al. 2015; Kayser-Jones 2002; 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 (Dwyer, Nordenfelt and Ternestedt 2008; Goodman et al. 2013; Ternestedt and Franklin 2006; 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 cohabitation (Djivre et al. 2012), feelings of abandonment and neglect due to the absence of family and the time poverty of staff (Franklin, Ternstedt and Nordenfelt 2006; Dwyer, Nordenfelt and Ternstedt 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 (Ternstedt and Franklin 2006; Österlind et al. 2017, Franklin, Ternstedt and Nordenfelt 2006, Kayser-Jones 2002). For residents in Dwyer's Swedish study (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 (Ternstedt 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 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, Nordenfelt and Ternstedt 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 Franklin et al.'s (2006) Swedish study, 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 (Tjernberg and Bökberg 2020; Djivre et al. 2012; Gjerberg et al. 2015; Kayser-Jones 2002; Sussman et al. 2017). 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 United Kingdom and the United States, 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 Australian study (2021), 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) (Parker 2011; Djivre *et al.* 2012; Davis-Berman 2011; Dwyer, Nordenfelt and Ternstedt 2008; 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 (Djivre *et al.* 2012; Munn *et al.* 2008; Whitaker 2010; 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 endeavor 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 (Österlind *et al.* 2017; Djivre *et al.* 2012). 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 based noted that dying in aged care entails a lack of choice about the location and management of death (Pleschberger 2007; Mathie *et al.* 2012; Sussman *et al.* 2017; Whitaker 2010). 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, Ternstedt and Nordenfelt 2006; Sussman et al. 2017; Whitaker 2010; Djivre et al. 2012; Frey and Balmer 2022; Wardle and Bennett 2021). For the Punjabi Indian participants in Wardle & Bennett's Australian study (2021), 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 (2021) 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 North American studies as a major impediment to the delivery of quality, relationally-focused end-of-life care (Djivre et al. 2012; Kayser-Jones 2002; Munn et al. 2008). 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 Djivre et al's study 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 (2012: 509).

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 (Fleming *et al.* 2016; Sussman *et al.* 2017; Gjerberg *et al.* 2015; Mathie *et al.* 2012; Whitaker 2010; Franklin, Ternstedt and Nordenfelt 2006; Ternstedt and Franklin 2006; Davis-Berman 2011; Djivre *et al.* 2012; Österlind *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, Ternstedt and Nordenfelt 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” (Österlind *et al.* 2017: 4; Fleming *et al.* 2016; Goodman *et al.* 2013). 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’s 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 centered 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, Ternestedt and Nordenfelt 2006; Dwyer, Nordenfelt and Ternestedt 2008; Davis-Berman 2011; Whitaker 2010; Pleschberger 2007; Mathie *et al.* 2012). A complex interplay of emotions underpinned these anxieties about dying in residential aged care. A resident in Ternestedt and Franklin's Swedish (2006) 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 (Ternestedt and Franklin 2006). A resident in Dwyer *et al.*'s study 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" (2008: 102). In studies across various countries, feelings of helplessness and incapacitation were linked to both bodily alienation and loss of identity (for example, 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, Ternestedt and Nordenfelt 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, Nordenfelt and Ternestedt 2008; Fleming *et al.* 2016; Österlind *et al.* 2017; Whitaker 2010). 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 residential aged care facilities as social worlds, comprising residents, families, and a range of staff, including visiting health care and allied health professionals. Every-day 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 underexamined 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, Seymour and Bellamy 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 (Johnstone *et al.* 2016; Kortes-Miller *et al.* 2018; Almack, Seymour and Bellamy 2010). 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 aging 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 United Kingdom, and the United States, 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 (Sussman *et al.* 2017; Parker 2011; Kayser-Jones 2002). 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.*, 2021). 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, for example safety measures and containments, and the consequences of enforced isolation and restrictions on visitors for social connection and quality of care (e.g., Hack *et al.*, 2022; Parks & Howard, 2021). Indeed, the pandemic has prompted a heightened awareness of anticipated death, with potential to profoundly refocus care within RACFs toward 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 & Phelan, 2020). Relational experiences, such as experiences of ‘saying goodbye’ to family (Hanna et al., 2020), and respect and agency in advance 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, for example 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.* 2021). 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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