

## Review

## Existential ageing and dying: A scoping review

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## ARTICLE INFO

## Keywords:

Ageing  
Death & dying  
Self  
End-of-life care  
Identity

## ABSTRACT

**Background:** After significant early interest in aging and dying, recent empirical studies have been few and theoretically fragmented.

**Objective:** The aims of this review were to map what is empirically known about the intersections between existential aging (a sense of passing years that evoke a sense of nearness-to-death) and dying identity and to describe the available evidence.

**Method:** Articles were reviewed employing PRISMA guidelines. Seven data bases were searched resulted in 165 records. Of these 165 records a final selection of 24 studies that met the criteria were examined.

**Results:** Evidence from the review found that the formation of the identity of dying alongside existential aging was associated with personal changes related to self/gerotranscendence, self-concerns about the inevitability of death (mortality salience), self-concerns about the prospect of death (death anxiety), attitudes toward the older self as a moderator of attitudes to death (aging attitudes), or simply anticipating the death of self (the future). Collectively, these studies found that death and dying were threats or challenges to life as an increasingly aging identity and that this seems to require compensation or accommodation.

**Conclusion:** These studies confirm the importance of nearness-to-death on identity formation and psychological change in older populations. However, most of the studies were quantitative and tested for pre-existing ideas and concepts. There is a need for more qualitative studies to search for wider or parallel meanings about identity change in the face of aging and death, more longitudinal designs, and greater attention to mixed methods approaches, especially for populations for whom talk or writing may be restrictive.

## 1. Background and objectives

*One does not just die all of a sudden. It is a process and one we may be conscious of for the last ten or twenty years of our life, which if you think about it, may be a quarter or more of your lifetime. I find myself wondering why this is not more talked about and why it has not become the common knowledge of our lives. I am self-conscious in writing about this. For after all, no one speaks of dying until they have only a few months or weeks or hours to live. This is society's definition of dying. It asks that I deceive myself and others about my daily awareness that my body is using itself up; it prevents me from calling this process by name for myself and others (McDonald & Rich, 1984:108-109).*

Dying as a biological process is a necessary but insufficient condition for the formation of dying as a personal and social experience. For dying to be 'felt' as a 'lived experience' it must, however briefly, form part of one's identity – the story about oneself. "I am a dying person" marks the recognition that I am aware that I will die very soon. I will die not merely

because I know I am a mortal being, *but more than this*, I will die because my end is in actual physical, social, or close temporal sight. In this way, passengers on a doomed flight who are aware of their fate become dying people, similar to many terminally ill cancer patients. After realizing the close proximity of their impending death, both groups make an assortment of behavioral changes that include adjustments, preparations, or social messaging to others.

On the other hand, some people whose terminal illnesses are severe, irreversible, and extensive, as judged by medical opinion, will always view themselves not as 'dying persons' but instead as 'fighters' and 'survivors' to the very end. Dying identity is a reorientation of the social self that entails an incorporation - not merely of the finiteness of one's own life - but of its inexorable and felt nearness (Kalish, 1966; Cassell, 1974; Kellehear, 2014). Previous social and behavioral studies have typically explored the dying identity in terminal illness contexts (e.g., Carlander et al. 2011, Lowrie et al. 2019) but seldom inside the experience of simply growing old. And yet, as the opening quotation keenly

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<https://doi.org/10.1016/j.archger.2022.104798>

Received 6 June 2022; Received in revised form 23 August 2022; Accepted 25 August 2022

Available online 31 August 2022

0167-4943/Published by Elsevier B.V.

observes, living-with-aging in later life must intrinsically, and perhaps more commonly than one might suppose, be bound up in a parallel experience of living-with-dying. We describe this experience as 'existential aging' - the experience of a sense of nearness-to-death gained from mainly a self-consciousness of the passing years, often led by a sense of growing chronology associated with vulnerability. This sense of vulnerability to death is, like the opening quote, associated primarily with this consciousness of passing years and not driven solely or mainly by illness, frailty or disability. Although both existential aging and illness aging experience may NOT evoke the identity of dying, most of the research has been devoted to studying that association. However, if this emergent existential, social psychology is a separate part of human development in later life - aside from illness and aging - then how precisely has this emergent identity of dying with existential aging been researched?

The scholarly literature at the intersections of existential aging and dying identity that might answer that question is only very recent and has been patchy at best, and often fragmented. Simmons (1945: 224-244) post-war, classic review of aging in hunter-gatherer societies observed that aging and dying were not only recognized identities in the past but were also supported by cultural customs and rituals from the wider family and tribal groups. This gives us some anthropological and historical precedent for believing that identities of aging and dying have commonly converged. But in modern industrial cultures, much post-war academic research into this form of identity development has focused on narrow institutional examples, sometimes hospitals and hospices, but mostly nursing home populations. Like Simmons, later work on the dying identity and aging focused on role change, altered interactional patterns, or narratives of the self. Empirical examples can be seen in the works of Kalish (1965), Preston & Williams (1971), Gustafson (1972), Marshall (1975), Gubrium (1975), and Lofland (1976).

In these and other works, there was recognition that the growing awareness of dying as part of the aging process, of advancing years, though definitely present in modern populations, varied widely in type and extent (Kalish, 1970), even when this identity (as role change or altered interactions) were recognized by professional and family caregivers (Glaser & Strauss, 1965, 1971). But for much of this early gerontological and thanatological research, the definitions of 'dying' occurred in a broader cultural context of social taboo that promoted interpersonal attitudes of non-disclosure, reticence, or social ambiguity (Aries, 1975; Veatch & Tai, 1980). This led to few studies that openly broached the topic of death, dying, and aging. Other early studies of dying with older adult samples employed understandings of dying that were not necessarily shared with or by the subjects at the center of the research (Fox, 1959; Sudnow, 1967; Matthews, 1976).

In more recent times there has been greater interest in research at the intersections of aging and dying largely because of the exponential growth of an older population and the nursing home sector, with parallel interest and growth of hospice, palliative care, and advanced care planning developments in healthcare (Kellehear et al., 2020). Some recent theoretical and philosophical work, often based on contemporary case studies and historical literature, has continued to examine the emergent identity of existential aging and dying. For example, Small et al. (2007), Kellehear (2014), and Baars (2017) are among recent monographs examining how awareness of impending death, 'finitude', or 'uncertain futures' contribute to evolved forms of identity that help initiate new forms of social conduct, personal reflection and soliloquy, and reorientation of values. These studies have emphasized narratives and meanings of the self. Kellehear (2014:205) notes how the toll of losses, and sometimes the transformations of multiple illnesses or institutionalization, or the processes of reminiscence specifically associated with aging, retirement, or perceived nearness to death create fertile grounds for a new existential sense of self-identity: "The world is inexorably altered. There is no turning back, nor is there any, or rarely any, biographical precedent for what is happening to the self".

However, this directly focused work on existential aging and dying

seems to have become uncommon in actual empirical research on the same topic. It is currently difficult to identify a clear body of empirical work examining this important intersection of dying identities in older adults. And yet it is important to do so, because currently the 'healthy aging' philosophy that dominates so much aged care literature frequently translates the eventual idea of end-of-life care as terminal care - care for the last weeks or days of life. If the experience of 'dying' is much longer than the 'terminal phase' - in fact may be more widely shared inside populations of so-called 'healthy older adults' as an existential identity change - we may well be under-supporting these populations in significant and serious ways. These populations may have their own separate public health consequences for co-morbidity, premature mortality, and quality of life.

Therefore, the aim of this paper is to provide a scoping review of recent empirical literature related to the emergent identity of dying in the older adult that asks: what is empirically known about the intersection between dying and existential aging as a felt experience linked mainly to the experience of 'growing older', and also, what is the nature of the evidence. As is usual in many scoping reviews, we map rather than synthesize the evidence and then describe the implications for future research. In line with the major purposes of scoping reviews then, as outlined by Arksey & O'Malley (2005), Levac et al. (2010), and Munn et al. (2018), our specific aims are to: (1) Describe and clarify the key concepts or definitions employed by this literature when currently exploring the intersections between dying and aging; (2) Identify the types of available empirical evidence about the intersections between dying and existential aging; (3) describe the main features of how this research on this topic is conducted; and in our final discussion, (4) Identify the main gaps in this current knowledge and to suggest some important ways forward.

## 2. Methodology

The methodology adopted by this scoping review is the PRISMA-ScR by Tricco et al. (2018).

### 2.1. Protocol and registration

At this time, no review protocol for this topic has been developed, finalized, or registered by the authors.

### 2.2. Eligibility criteria

Studies that examined samples of older people over the age of 60 were included. However, the literature was not limited to any ethnic group, geographic location, or original language publication as long as an English translation of the original article was readily available in the scholarly databases searched. Timeframe was limited to articles published between January 2010 and present day. Searches were limited to articles published in peer-reviewed journals; books, opinion pieces, and literature reviews were excluded as the objective of the scoping review is to determine the breadth of original research on the topic rather than an analysis of the existing original research.

### 2.3. Information sources

This scoping review was conducted using the following databases: Ovid Medline, Academic Search Premier, Cinahl, CatQuest (University of Vermont libraries specific), PsychArticles, Embase, and PsychInfo. The searches were conducted beginning on 12/3/21 and concluded on 1/3/22. These databases provide the most comprehensive coverage of all the major journals in medicine and healthcare, and the behavioral and social sciences including gerontology, thanatology, psychology, human development, sociology, and anthropology.

## 2.4. Search strategy

The keywords used variously in the searched databases were intended to restrict the results to specific studies of identity changes resulting from nearness to death due to aging. To re-emphasize, *our review was to identify how growing old itself might influence the emergence of dying and not illness-related factors in the multimorbidity of aging*. Our focus has been on self-understandings, attitudes, or behaviors linked to new identities shared with ‘growing older’ that might include the prospect of death or dying. While the ‘sense of dying’ has been widely linked to illness and disability studies, especially in palliative care, we were interested in how merely a sense of growing chronologically older – or ‘being old’ – might play a similar role in identity formation in its own right. Therefore, in the initial searches, when possible, efforts were made to exclude sources tagged as related to suicide, or studies of illness-specific populations, such as cancer patients. Table 1 specifies the search strategies used for the various databases, depending on the search options available in each respective database.

## 2.5. Selection of sources of evidence

Articles that met the initial search criteria were initially deduped to eliminate those that appeared in multiple databases. During this first review, all articles were screened by abstract and title, and separated into two broad categories: included and excluded. The decision to include or exclude sources during this initial review was based upon whether they appeared to be relevant specifically to the concept of an evolution in personal identity as one approached the end of life through aging.

The articles excluded fit into several categories. Because each database had distinct inclusion/exclusion criteria, the first articles eliminated included those that met initial exclusion criteria, such as those related to suicide, condition-specific studies, or widowhood. Articles that were not specifically relevant to dying and identity formation were then excluded, as were any sources referencing multi-age studies rather than elder-specific studies. Further articles were excluded by virtue of being too restricted in scope, such as those that were environment (i.e., residential hospice or nursing facility), or religion (through the

parameters of specific religious practice, rather than simply studying a cohort specific to a certain religion) specific. Finally, articles were excluded that focused *solely* on terror management, death anxiety, or mortality salience if they did not connect this to a study of how these experiences connect to an evolving dying identity while aging. Details of these exclusion criteria are detailed in Table 2 below.

## 2.6. Data extraction and analysis

The remaining articles were then “clustered” into categories relevant to their potential influence on or as a result of identity development and the full text of the articles was reviewed. After this review, 5 additional articles were excluded (as shown in Table 2). Remaining articles were analyzed thematically for empirical orientation and for underpinning conceptual frameworks. The initial analysis was conducted independently by both authors and then cross-compared and any differences resolved by mutual re-examination of the sources. Discussion of articles deemed as relevant follows.

## 3. Results

24 studies that met the inclusion criteria were derived from the review process. These articles were found to have relevance specifically to the evolution of a “dying” identity as one aged. Most of these studies draw from a psychological approach to their subject with the remainder drawing upon health promotion/ community health theory. No sociological or anthropological studies specifically on aging and dying were identified. The notable absence of studies from this tradition may in part be due to not employing keywords sensitive to this epistemology – such as ‘experience’ or ‘understanding’. Equally likely however, the over-identification of studies of dying with illness dying, including in residential care settings, may account for the seeming lack of work in this area by these disciplines. The current bias in studying dying as experiences of embodiment, especially inside experience of frailty or illness as opposed to self-understandings not related to those experiences, may also play a role in explaining the lack of studies in this area and from these fields (Kellehear, 2009, 2017). Details of these relevant studies are presented and organized around the first three aims of our review: (1) describing and clarifying the key concepts/definitions of aging and dying underpinning the studies; (2) summarizing the types of empirical evidence used in the studies, and (3) describing the main features of how this research is conducted. Identifying the gaps in the current research and identifying ways forward are addressed in the final discussion and implications section of this review Table 3.

### 3.1. Describing and clarifying key concepts or definitions of aging and dying

#### 3.1.1. Identity – the changing sense of self

Of the 24 studies reviewed only 5 studies focused directly and explicitly on the emergent identity of dying in old age. Most of these studies used a handful of theoretical ideas drawn from the broad field of behavioral sciences. McCarthy et al. (2019) explored the idea of ‘self-transcendence’. This was described as an experience of expanding self-boundaries of meaning beyond an older person’s ideas about growing old. This expansion of self-boundaries is enabled by including a more integrated view of the self with the wider world, but particularly the spiritual and social ‘cosmos’. In this study, an educational program was employed and evaluated to enhance this expanded experience of the self. It was noted for the 20 participants in this study, that the idea of death as a part of the lifecycle was a key part of the contemplation of their own future. Death was a topic central to their discussions, and this in turn, was linked to their own ability to enable self-transcendence of their experience of aging and decline.

A related idea was examined by Hoshino et al. (2012) in their study of over 500 community-dwelling, older, Japanese people. This study

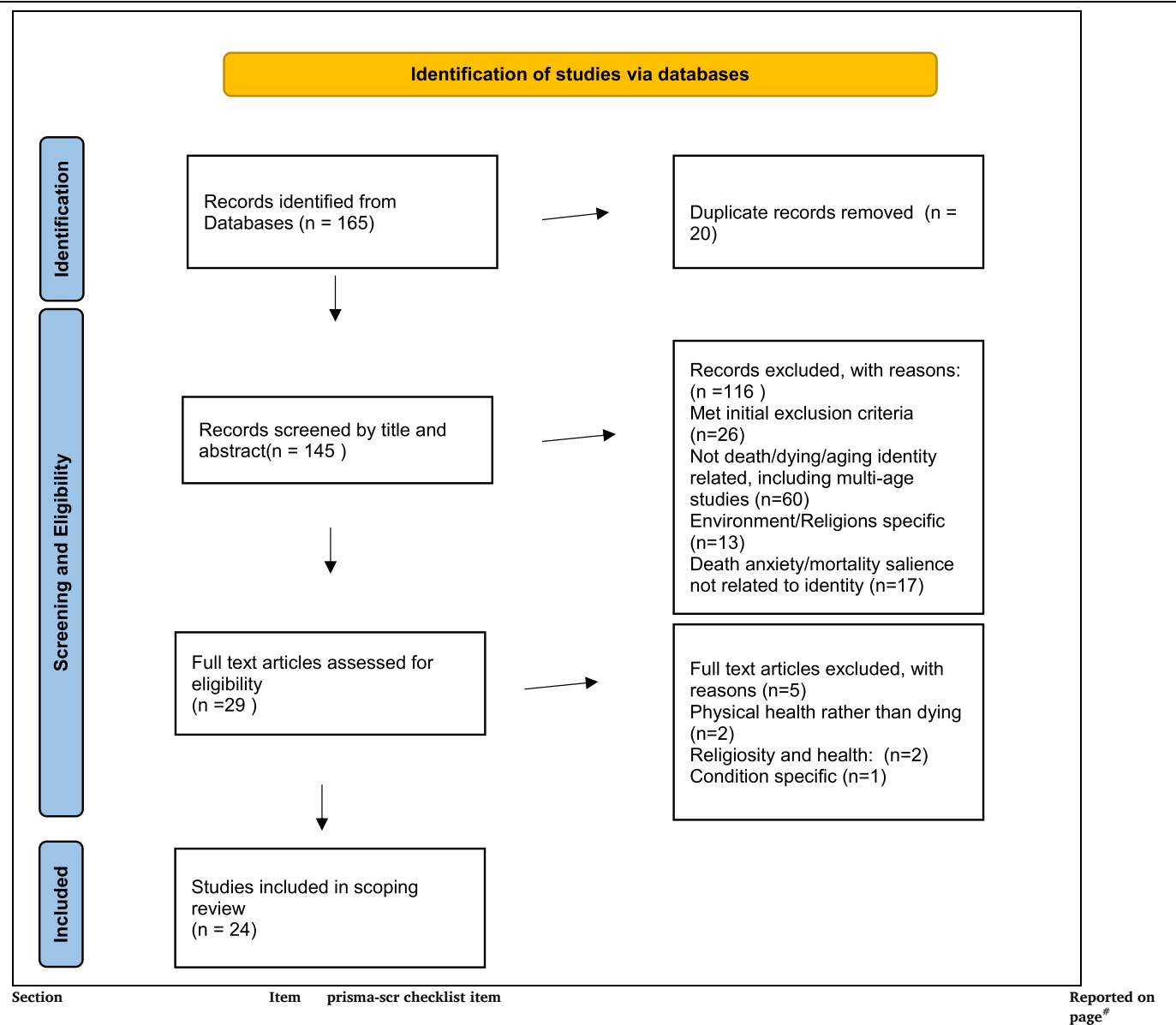
**Table 1**

Caption missing.

Database	Key searched terms included	Preliminary results
Ovid Medline	Included: Aged/Attitude to Death/Self-Concept. Excluded: Suicide/Euthanasia/Cancer/Hospice	36
Academic Search Premier	Included: Aging, elderly, older adults, seniors, geriatrics/Attitude to Death/Self-concept, self-worth, self-perception, self esteem Excluded: Euthanasia, assisted suicide, right to die, physician assisted death, death with dignity/Cancer patients, oncology patients, patients with cancer, neoplasms/Widow, widowhood, widower, loss of spouse/Hospice, palliative care, end of life care, terminal care/Young adults, emerging adults, young adulthood	69
Cinahl	Included: Aging/Attitude to Death/Self Concept	12
CatQuest	Included: Elderly/Older Persons/Self Concept	12
PsychArticles	Included: Aging/Attitude to Death/Self Concept	20
EmBase	Included: Aging/Attitude to Death/Self Concept/ Excluded: cancer/suicide	5
PsychINFO	Aging/Attitude to Death/Self Concept	11

**Table 2**

Preferred reporting items for systematic reviews and meta-analyses extension for scoping reviews (PRISMA-ScR) checklist.



(continued on next page)

Table 2 (continued)

Data charting process <sup>†</sup>	10	Describe the methods of charting data from the included sources of evidence (e.g., calibrated forms or forms that have been tested by the team before their use, and whether data charting was done independently or in duplicate) and any processes for obtaining and confirming data from investigators.	N/A
Data items	11	List and define all variables for which data were sought and any assumptions and simplifications made.	5
Critical appraisal of individual sources of evidence <sup>‡</sup>	12	If done, provide a rationale for conducting a critical appraisal of included sources of evidence; describe the methods used and how this information was used in any data synthesis (if appropriate).	N/A
Synthesis of results	13	Describe the methods of handling and summarizing the data that were charted.	6
<b>Results</b>			
Selection of sources of evidence	14	Give numbers of sources of evidence screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally using a flow diagram.	27
Characteristics of sources of evidence	15	For each source of evidence, present characteristics for which data were charted and provide the citations.	27
Critical appraisal within sources of evidence	16	If done, present data on critical appraisal of included sources of evidence (see item 12).	N/A
Results of individual sources of evidence	17	For each included source of evidence, present the relevant data that were charted that relate to the review questions and objectives.	27
Synthesis of results	18	Summarize and/or present the charting results as they relate to the review questions and objectives.	27
<b>Discussion</b>			
Summary of evidence	19	Summarize the main results (including an overview of concepts, themes, and types of evidence available), link to the review questions and objectives, and consider the relevance to key groups.	6-17
Limitations	20	Discuss the limitations of the scoping review process.	18
Conclusions	21	Provide a general interpretation of the results with respect to the review questions and objectives, as well as potential implications and/or next steps.	19-21
<b>Funding</b>			
Funding	22	Describe sources of funding for the included sources of evidence, as well as sources of funding for the scoping review. Describe the role of the funders of the scoping review.	N/A

JB1 = Joanna Briggs Institute; PRISMA-ScR = Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews.

\* Where sources of evidence (see second footnote) are compiled from, such as bibliographic databases, social media platforms, and Web sites.

† A more inclusive/heterogeneous term used to account for the different types of evidence or data sources (e.g., quantitative and/or qualitative research, expert opinion, and policy documents) that may be eligible in a scoping review as opposed to only studies. This is not to be confused with information sources (see first footnote).

‡ The frameworks by Arksey and O'Malley (6) and Levac et al. (7) and the JBI guidance (4, 5) refer to the process of data extraction in a scoping review as data charting.

§ The process of systematically examining research evidence to assess its validity, results, and relevance before using it to inform a decision. This term is used for items 12 and 19 instead of "risk of bias" (which is more applicable to systematic reviews of interventions) to include and acknowledge the various sources of evidence that may be used in a scoping review (e.g., quantitative and/or qualitative research, expert opinion, and policy document).

looked to explore and adapt the idea of gerotranscendence to a Japanese population. Gerotranscendence, similar to self-transcendence, is an idea developed by Swedish gerontologist Lars Tornstam. Tornstam suggests that, as one ages, people develop a redefinition of the self that involves a new understanding of fundamental existential questions, the self in relation to others, an increasing attraction to 'positive solitude', and a feeling of cosmic communion with an identification with past generations. This can be associated with less emphasis on material things and self-preoccupation (Tornstam, 1989).

Weiss (2014) explored the dual-age identity model that he postulated some years before (Weiss & Lang, 2009). In this way of thinking, Weiss argues that two age related identities emerge in later life – one that increasingly identifies with one's own age group and the other that begins to identify with their own generation (one's cohort). Attempting to positively offset the multiple losses associated with aging will influence many older people to identify with their own generation. However, the tendency to identify with one's specific age group might be associated with a less functional preoccupation with personal loss and decline. In this way, the dual-age identity model reflects the theoretical assumption that older people who recognize their proximity to death as part of their own self-story wish to compensate for the challenging impact derived from that realization by seeking ideas or experiences that can take them beyond that burden of understanding – they wish to 'transcend', to go beyond the stresses of the emergent realization of death and dying in their sense of self.

Nakagi & Tada (2014) employ a broader but no less psychological conceptual approach by exploring Erikson's idea of 'ego integrity'. Using this idea, Nakagi and Tada argue that successful 'integrity' in life provides a counter influence against mid to later life despair – accepting one's whole life with all its good and bad experiences and finding significance and value in that process. This inevitably means, at least in

so-called successful aging terms, that the older person who can integrate impending death into their sense of self is able to manage their own fear of death, able to contemplate it directly, and display a positive attitude toward it as part of their sense of aging. In all these studies, the 'dying' identity described and tested for by McCarthy et al. (2019), Hoshino et al. (2012), Weiss (2014) and Nakagi & Tada (2014) are united in their suggestions that the aging self is a compensating identity that seeks to dissipate or rebalance the emergent identity of dying because it is a *troublesome or challenging one in intrapsychic terms*.

Finally, Hutnik et al. (2012) asked 16 UK centenarians what it feels like to be 100 years of age. Unfortunately, their main interviewing strategy was to ask, "Tell us about your life". Although talking about death was a key theme, all the recipients did not speak about this topic in relation to themselves. The oblique and atheoretical approach to identity formation and change did not yield any self-concepts. A lack of direct prompts about approaching death or attitudes to their sample's own future meant little detail was yielded in the way that this age group integrated death into a sense of self.

In summary, the main concepts explored by these studies to elucidate an emergent dying identity in old age were self-transcendence, gerotranscendence, dual-age identity formation, and ego integrity. These studies demonstrate a dominance of psychological concepts supported by the assumption that death and dying are threats or challenges to an existing aging identity requiring compensation or accommodation. Other studies that did not explore identity as a core idea did nonetheless generate important and related concepts that were relevant to a study of the convergence of aging and dying.

### 3.1.2. Mortality salience - self concerns about inevitability of my own death

There were seven studies that explored the impact of the feeling of the inevitability of death on the self. These series of studies explored the



nature and impact of the inevitability of death on older people. Bergman & Bodner (2020) observed that a heightened sense of one's age, low self-esteem and feeling closer to death promoting depressive feelings. Fung et al. (2020) observed that it was not simply a 'sense of impending death' that prompted a sense of the inevitability of death but rather specific reminders from practical experiences/events of death and loss that created that new awareness. Palgi et al. (2010) observed that lower subjective ratings of wellbeing were better predictors of actual dying than subjective ratings of one's own health. However, because this study defined dying as 'functional decline' it is not clear whether it was functional decline that led to a sense of lower wellbeing or the reverse.

Zaslavsky et al. (2015) assessed measures of optimism vs pessimism in an older sample of adults and observed that optimists maintained a higher quality of life compared to pessimists although the differences became small as each approached actual death. Shrira et al. (2015) observed emotional complexity (feeling more than one emotion at the same time) decreased as one moved closer to death and this was viewed as a negative response since the authors argued that emotional complexity can be helpful near death. Luth (2016) observed, contrary to expectation, that a limited future time perspective is not associated with greater advanced care planning in community dwelling older adults. Finally, Voss & Kornadt (2017) found that holding a positive or negative self-view of the future had a self-fulfilling prophecy effect on actual future events and experiences as positive or negative.

In summary then, the personal inevitability of death helps shape one's identity as an older person more than simply 'being old'. A variety of personal characteristics such as optimism, self-esteem, or personal outlook for the future help shape how death is viewed. At the same time, the nearness to death and specific practical reminders of that nearness, can have significant impacts on subjective wellbeing and morale more generally. Most of these studies confirm the importance of nearness to death on identity formation and psychological change but say little about any changes to and within interpersonal networks and experiences.

### 3.1.3. Death anxiety - self concerns about the prospect of death

There were six studies exploring self-concerns, but specifically anxieties, about the prospect of death. Unlike the studies exploring the personal response to the inevitability of death, these studies focusing on the prospect of death made the *a priori* assumption that the main response will be anxiety and fear. Azaiza et al. (2010) observed that death anxiety in their sample of older Arab Muslims could refer to almost anything – fear of threat, unease, fear of the unknown, or anything negatively associated with death. Kaur Kang & Kaur Kang (2013) explored what they termed as 'thantaphobia' among their older Indian sample. The assumptions underpinning their study were openly Freudian, drawing upon the work of Erikson and Freud. Missler et al. (2012) confirmed the pattern of earlier findings from Azaiza et al. (2010) that so-called fear of death was more specifically fears about particular aspects of death and dying and these were not uniform. Some feared the process of dying rather than death itself while others were anxious about the welfare of others after they had died. Wettstein et al. (2015) survey of Germans aged between 87 and 97 years of age revealed high levels of acceptance of death and low levels of anxiety. They argued that this finding reflects the continued lack of concordance in previous studies of death anxiety. Adelirad et al. (2021) revealed that the fear of death among Iranian men was linked to their sense of aging while the same anxiety in women was linked to perceived social support. Finally, Shrira et al. (2014) observed that subjective sense of age was more important than actual age when assessing the influence of age on distress and nearness to death. None of these studies purported to use Terror Management Theory – the underpinning theory for Bodner & Bergman (2019) and Bergman & Bodner (2020). However, the studies in this category are linked to these theories in one important way: they assume that the prospect of death has, or probably has a mostly negative impact on the self.

### 3.1.4. Aging attitudes - attitudes to older-self shape attitudes to death

Four studies explored the role of attitudes towards aging and death. Zhang et al. (2020) conducted a public health study that linked negative attitudes to aging to poor lifestyle choices and reduced survival. Siebert et al. (2018) followed 260 healthy people over the age of 62 for twelve years and found that negative attitudes toward their own aging was a significant risk factor for developing cognitive impairment and Alzheimer's Disease. Van Homboldt et al. (2014) explored a range of factors in over-75s that might predict better adjustment to growing old – from subjective wellbeing, lifestyle, demographic, and health factors and found that 60% of the variance was attributable to spirituality. Spirituality mainly referred to existential meaning, but this factor was also linked to higher social activity, support, and shared meanings with others. Finally, Bodner & Bergman (2019) explicitly exploring the idea of terror management in aging found that positive body image moderated fear of death. In summary, these four studies highlight how negative images of aging court poor outcomes in physical and mental health. The link between seeking wider meanings in spirituality, social networks, or health maintenance, and a more positive sense of self despite nearness to death supports the earlier work about positive examples of the convergence of aging and dying observed in the specifically identity-oriented studies above.

### 3.1.5. The future - anticipating death of the self

There were two studies concerning the anticipation of death that examined this idea indirectly – through the lens of perceived future. Van Leuven (2011) asked 18 people over the age of 75 about their own self-rated health and their advance care planning activities. They found those who were in good health tended to have advance care plans and those in poor health had none. More interestingly, Mathie et al. (2011) conducted a study of 63 residents of a UK care home. These researchers specifically prompted residents for their ideas about the future and about death. The study found four distinct groups with only one group (of seven people) who were able to anticipate their own death and talk explicitly about plans and wishes. The other groups, most of the participants in the study, did not engage in any discussion of death and preferred instead to live in the past or the present. These people did not consider that they had a 'future'. Others, chose to speak in terms of living 'day-to-day', and while many accepted that they would live in the care home 'until they died' did not consider making end of life care plans or reorientating themselves in accordance with that realization necessary. Many of these same people were more concerned with the welfare of others after they had gone.

The final study by Mathie et al. (2011) suggest that although aging and dying identities do converge in sites such as care homes, such identities may not represent most older people. Unlike the early Simon's observations of those living and dying in hunter-gatherer societies, the convergence of aging and dying, although in evidence, may not be particularly important or as ascendent for older people in 21st century industrial economies. However, it is not clear if the study assessing futures by Mathie et al. is a reliable indicator of the convergence of aging and dying because although the sample appears to be stable (care home residents) the population may not be. In other words, there may be several populations of 'old and dying' people in the studies care home – some who were once able to anticipate and talk about their death and who engaged in plans and wishes but now, having done so, wish only to 'wait' for death or live for the day. Others who have not done this 'earlier' work but are now willing to do so act because of their entry into a nursing home. Unless a longitudinal element (even mere inquiries about resident histories of anticipating death/dying) that precedes entry into the care home is present we are unable to untangle the possibilities of a process of aging and dying (or the ongoing changes people make about their beliefs in a personal future) from these kinds of cross-sectional studies.

In summary then, the key aspects of the self while aging and dying that are explored by recent studies are: the changing sense of self

**Table 3**  
Characteristics of studies included in the scoping review.

Study findings	Aim	Methodology	Population/setting	Theory	Key
1. McCarthy et al. (2019)	explore idea of self-transcendence In older adults	mixed methods	20 community dwelling (over 60 yrs)	transcendence	new perspective on life & death gained
2. Hoshino et al. (2012)	develop gerotranscendence Scale for Japan	survey	525 community-dwelling (60-94 yrs) Japan	gerotranscendence	scale is applicable
3. Weiss (2014)	hypothesis test to invest If dual-identity model changes with aging	experimental & cross-sect correlational design	341 community-dwelling (18-81 years)	dual-age identity	recognition of impending death req transcendence
4. Nakagi & Tada (2014)	clarify relationship between Identity development stages and death anxiety among elderly	survey, scales + interview	427 community-dwelling (60-85 years)	ego integrity	integrating death identity while aging has positive benefit
5. Hutnik et al. (2012)	identify social themes in the Narratives from centenarians	interviews	16 care homes + community (mean age = 101) UK	atheoretical	Happy to talk about death but not their own
6. Bergman & Bodner (2020)	identify connection between age awareness and depression and assess how nearness to death mediates this	online survey/scales	386 community dwelling (60-97) Israel	terror-mgt	age awareness assoc. with increas subj nearness to death results in depression but this mediated by self-esteem
7. Fung et al. (2020)	contrast the effects of limited Future time and mortality salience. In goal prioritization	Computer-lad exercises.	438 community-dwelling (18-85) Hong Kong	Selectivity Theory terror mgt	future time limits has greater effect than mortality sal
8. Palgi et al. (2010)	as perceived death approaches What declines more - subj health Or subj wellbeing?	survey + interviews	1360 community-dwelling (75-94) Israel	Not Stated	Subj wellbeing exp greater decline than subj health related to distance-to-death
9. Zaslavski et al. (2015)	assess dispositional optimism role in QOL as a function of age or distance to death.	survey/scales	2096 enrolled in trial (59-93) USA	Not Stated	optimism helps maintain +ve/QOL in face of age related decline and death-related trajectories
10. Shrira et al. (2015)	assess emotional complexity and its effects on distress as function of age and distance to death	survey/scales	188 community dwelling (40-80+) Israel	Not Stated	emotional compl decreased with perceived close to death.
11. Luth (2016)	Is perceived near-to-death assoc with ACP	survey	305 community dwelling (55-91) USA	Not Stated	Limited time persp have no impact on ACP
12. Voss & Kornadt (2017)	What role do personal views of one's future play on actual health outcomes	2-point survey	593 community dwelling (30-80) Germany	Not Stated	self-fulfilling prophecy observed
13. Azaiza et al. (2010)	assess death anxiety in older Arab Muslim people	survey	145 community dwelling (Av.age 74) Israel	Not Stated	support networks decreased death anxiety
14. Kaur Kang et al. (2013)	assess death anxiety in older Indian people	survey	120 community dwelling (65-80) India	Not Stated	optimism lessened death anxiety
15. Missler et al. (2012)	explore key features of death Anxiety in older people in care	survey	48 in care home (60-96) The Netherlands	Not Stated	death anxiety high but multi-faceted/diverse meanings
16. Wettstein et al. (2015)	explore wellbeing in the older Old	Longitudinal surveys	124 community dwelling (87-97) Germany	Not Stated	high levels of death acceptance
17. Adelirad et al. (2021)	assess death and aging anxieties In Older tranians	survey	450 community-dwelling (60-96) Iran	Not Stated	death anxiety link with aging in men and lack of social Support in women
18. Shrira et al. (2014)	Explore link between subj age And distance to death on distress	survey	1073 community dwelling (50-86) Israel	Not Stated	subj age more NB than actual in death-related Distress
19. Zhang et al. (2020)	explore self-perception of aging and death on the older old	survey	9683 community dwelling (78-118) China	Not Stated	-ve age self-image court poor lifestyle higher mortality
20. Siebert et al. (2018)	explore self-perception of aging on subseq cognitive decline	Longitudinal survey	260 community dwelling (mid 60s to mid 70s) Germany	Not Stated	-ve age self-image linked to cognitive decline
21. Van Humboldt et al. (2014)	develop predictors of adjustment To aging in comm dwell older Adults	survey	1270 community dwelling (75-102) Portugal	Not Stated	Spirituality NB to adjusting well to aging
22. Bodner & Bergman (2019)	explore links between +ve body Image and management of death anxiety	survey	386 community-dwelling (60-97) Israel	Not Stated	+ve body image helps moderate fear of death
23. Van Leuven (2011)	assess impact of health status On adv care planning	focus group	18 mix community and residential care	health promotion	healthy more likely to engage with ACP
24. Mathie et al. (2011)	explore views of Eol among older people in residential care homes	interviews	63 care home residents (61-102) UK	Not Stated	only a minority of participants spoke about own death

(identity), self-concerns about the inevitability of death (mortality salience), self-concerns about the prospect of death (death anxiety), attitudes toward the older self as a moderator of attitudes to death (aging attitudes) and anticipating the death of self (the future). Underpinning the orientation of this empirical research were 6 major conceptual frameworks: these were self-transcendence, gerotranscendence, dual-age identity formation, ego integrity, death anxiety/terror-

management theory, and awareness of finitude.

Most of these concepts represent a research effort employing top-down theorizing that fails to make a broad assessment of personal and social experience. Instead, concepts are tested for their evidence within the population and not the development of new concepts from an inductive exploration of their experience. There were only two qualitative studies in this group of 24. Most of the concepts are singularly

derived from psychology – there is little to no evidence of inter-disciplinarity; no evidence or exploration of social, contextual, or cultural concepts (e.g. dramaturgical role, interactional ritual, rites/status passage). Most of the concepts assume aging and death/dying to be a threat that requires personal management or adjustment. There are no equivalent studies of wellbeing in aging or death/dying represented in this group of 24 studies.

In the three qualitative studies conducted in this area, one was atheoretical and failed to make specific probes related to death and dying. One other qualitative study was attempting to assess a short course, while the other remaining studies viewed the lack of any *evidence of anticipating death* as a *lack of anticipating death* despite the design limitations of the study itself to draw that implication. These technical observations about the key concepts used in this research highlights not solely the narrowness of the concepts employed but also the subsequent types of empirical evidence generated by them and of interest.

### 3.2. Types of available empirical evidence

21 studies reviewed here employed a variety of quantitative methods. Of these studies, 15 studies either employed survey questionnaires together with the administration of scales (Hoshino et al., 2012; Azaiza et al., 2010; Missler et al., 2012; Wettstein et al., 2015; Adelirad et al., 2021; Shrira et al., 2015; van Homboldt et al., 2014), or surveys only (Luth, 2016; Voss & Kornadt, 2017), surveys together with interviews (Nakagi & Tada, 2014; Shrira et al., 2014) or an online survey (Bergman & Bodner, 2020). Other studies employed solely the administration of scales (Weiss, 2014; Kaur Kang & Kaur Kang, 2013; Bodner & Bergman, 2019). Three studies used existing sources (Palgi et al., 2010; Zaslavsky et al., 2015; Zhang et al. (2020)), usually data sets from pre-existing studies or from government sources such as registries. Finally, one study collected medical/health screening data about general and cognitive health and another study (Fung et al., 2020) employed a combination of computer tasks, interviews, and scale administration.

There were four studies that employed interviews alone (Mathie et al., 2011; van Leuvan, 2011; Hutnik et al., 2012; McCarthy et al., 2019), with two of these using qualitative interviews with individuals (Mathie et al., 2011; Hutnik et al., 2012), one using focus group interviews (McCarthy et al., 2019), and the final study employing a structured or semi-structured style of interviewing (van Leuvan, 2011).

In summary then, the dominant type of empirical evidence provided by the vast majority of studies into the intersections between aging and death/dying were quantitative. There were only three studies in our review that attempted to provide qualitative type evidence. In philosophical terms, there were no mixed methods studies at all, although there were technically studies that combined different quantitative methods – scales with surveys, structured interviews with surveys, or computer tasks with structured interviews. The studies of existing sources were analyses or re-analyses of data originally collected by survey or structured interviews by prior researchers. Mixed-methods approaches that combine different philosophical considerations to capture different aspects of social reality (eg meanings vs their prevalence, or inductively derived themes vs hypothesis-testing), as for example, ethnographies or qualitative interviews combined with surveys or existing sources, were nowhere evidenced. There was no evidence of combining quantitative and qualitative methods.

Furthermore, of the three qualitative studies, all employed interviews solely. There was no evidence of attempts to provide or combine other forms of qualitative evidence for their findings. For example, there is no qualitative data from ethnography, participant or non-participant observations, autoethnography, memory work, or the study of existing personal sources such as diaries, letters, and other correspondence, to name only a few other methodological examples from the qualitative traditions.

### 3.3. Features of how the research on this topic is conducted

The emphasis on quantitative methods and the paucity and narrowness of the existing qualitative studies, such as they are, is a rather surprising finding given the topic area of the intersection between aging and death/dying. Even for studies that purport to study the impact of this intersection for identity change and transformation, there is little evidence of interest in personal experience itself - to collect an array of mortality meanings to self and subsequently, to discern patterns of these meanings among a larger or wider sample. Hypothesis-testing of pre-conceived concepts seems to have been the priority rather than the discovery of novel ideas, existential experiences, or attitude that might play a role in shaping identity at the end of life among older people.

Of those qualitative studies that seemed to share, or partly share an epistemological vision of research as meaning and narrative discovery, all studies appear to assume that these meanings can be reliably discerned through talking methods only. Given the cultural ambiguity, interpersonal pressures, and changing social customs and taboos concerning aging, dying, and death over the last half century of research, the reliance on methods that privilege talk seems methodologically risky or unreliable.

There is also a preponderance of cross-sectional designs and over-attention to community dwelling samples of older people. In social and behavioral studies of illness-related experiences of dying, it is widely acknowledged that ‘dying’ is not an event but rather a process over time. People come to realize they will die through an assortment of prompts such as observing their own worsening bodily changes, other people’s reaction towards them, prognostic awareness and acceptance, or cessation of curative treatments in the context of worsening symptoms. The lessons learned in these more medical/healthcare settings seem not to have been transferred to experiences of existential aging and dying contexts. There were only four longitudinal studies that supported their interests in aging and dying by acknowledging this process and designing their studies accordingly (Palgi et al., 2010; Wettstein et al., 2015; Zhang et al. (2020); and Siebert et al., 2018).

The over-attention to community dwelling samples in these studies saw only four exceptions – two studies that investigated care homes (Mathie et al., 2011; Missler et al., 2012), and two others that conducted their studies with both care home and community dwelling samples (Hutnik et al., 2012; Azaiza et al., 2010). If a social prompt is important to the development of a ‘dying identity’ than it might be expected that admission to a care home (voluntary or not) might be an important one. Longitudinal studies that follow community dwelling older people in their transitions to care homes (compared with those who do not make this transition) might also be expected to be valuable sources of data for understanding the convergence of aging and dying for older people in these contexts and transitions. But these designs are not a major feature of how these studies are conducted except for the two studies conducted by Hutnik et al. (2012) and Azaiza et al. (2010).

Furthermore, the theoretical approach in studies that test for age and death-related concepts tend to hold negative preconceived notions of both. In these studies, death is (*a priori*) interpreted as threat, and aging an inexorable decline toward it. Older people must defend, accommodate, dissipate, or deny their anxieties, fears, dread – or adapt. Whether this interpretation is universally true (as asserted by death anxiety/terror management theorists and other behavioral studies influenced by a psychoanalytic theory) is less important than asking whether these emotional reactions are the *sole* or dominant response to the prospect of dying or death.

Again, in social studies of dying with terminal illness we know that there have been positive transformations to identity, attitude, social relations, and personal outlook and values during the process of shifting from the experience of health, to illness, and then to dying. These positive experiences include role changes, values clarification, positive reminiscence, meaning making, greater intimacy in social relationships, the development of personal courage, spiritual awareness and growth,



greater social preparedness, and perceptual renewal and interest in the wider physical and social worlds (Carlander et al., 2011; Kellehear, 2014; Lowrie et al., 2019). Although some of these qualitative changes have been noted, particularly by studies examining transcendence or gerotranscendence (Hoshino et al., 2012; Nakagi & Tada, 2014; and McCarthy et al., 2019), these more positive changes have been seen within a narrow framework of biological and psychological factors and not a cultural pluralism that implicates and describes social or contextual influences.

Finally, of the 24 studies reviewed there were none conducted in indigenous societies or cultures. The continents of Africa, South America, and the countries of the Pacific region are not represented. Although there are ample studies among the 24 drawn from the USA, UK, and the EU region, as well as Asia (Japan, China, and India) and the Middle East (Israel and Arab Muslims), all of these studies – perhaps because of the emphasis on surveys, interviews, and scales – leave out indigenous experience and those of illiterate populations across the world. The international study of experiences of aging and dying has been limited because the methodologies employed have been very culture-specific, or because work in some of these regions has not yet appeared in English language periodicals. Our empirical understandings of the emergence of the dying identity in old age has thus far proved to be narrow by research design, limited in theory and concept use, and restricted by population and cultural sampling.

#### 4. Limitations

The intertwined problem of aging and multimorbidity imposes some important dilemmas on our choice of studies to review. How does one separate studies of the ‘existential experience of aging’ from the common experience of managing illness so commonly associated with aging in everyday life? Perhaps the palliative care or cancer literature can reveal a wider source of studies of the emergent identity of dying in old age as these populations enter palliative care or cancer treatment settings. This literature might also offer a wider array of both research design and theory on the intersections between aging and dying. However, the representativeness of that literature (a) for those in care homes or (b) for community dwelling older people who do not (through epidemiology, stage of illness, choice, or access barriers) use these kinds of services may be questionable. How is one to compare *life-limiting illness* with *life-limiting aging as an existential experience* as this is experienced *primarily* through non-health related prompts, that is, through changing body image, experiences of retirement, or a growing awareness of ‘finitude’? And if we were to open our review to this palliative care literature on aging and dying, a clearly overlapping if smaller population in epidemiological terms, might we risk a misleading conflation? Illness dying at any age (i.e., terminal illness) may be distinct from aging dying (i.e., nearing the end of one’s lifespan) and may therefore be characterized by distinct human experiences, needs, and behaviors that might suggest very different health and social care policy implications.

We have also excluded the suicide and requested death/euthanasia literature, and this too may be a limitation of our understanding of available research designs, concepts, and evidence for the emergent identity of dying in old age. This may have excluded some studies that might logically seem associated with this review. For example, the recent work of van Wijngaarden et al. that examined wishes to die by older people may suggest an examination of dying identity but may not be unequivocally in that genre of work. Some of this work represents studies of Tiredness of Life (ToL) or Weariness of Life (WoL) (van Wijngaarden et al., 2018; Appel & van Wijngaarden, 2021) and strongly suggest a desire to avoid a dying identity or process by opting for suicide – a sudden death. In fact, van Wijngaarden et al. (2015) suggests that maybe the participants in their study are less ‘dying people’ than in fact people whose identity are those of lonely, irrelevant, and socially unnoticed members of society whose greatest existential fear is

dependency in a friendless world. ‘Dying’ – as a physical and social experience – would be welcome but it is not their current situation or existential identity – it is an aspiration. In fact, similar to other studies of the wish to die, it is not ‘dying that most people desire in these populations but rather ‘to become dead’. ‘Dying’ is viewed as the very ‘dependent’ identity they wish to avoid. Death, not dying, is more precisely the existential and medical aspiration.

Furthermore, the international suicide rate is highest or second highest for the elderly (Conejero et al., 2018). Most people who avail themselves of euthanasia services in the US and elsewhere tend to be over the age of 60 (Steck et al., 2013). Much of what we learn about the motivations for these populations come to us through the study of the notes, letters, and diaries of those people who choose to end their own lives. However, the global prevalence of suicide is approximately 1.3% of all deaths (WHO, 2019) and this would suggest a limited generalizability for this specific population of older people as a subgroup from all older people.

#### 5. Discussion and implications

The aims of this review were to explore what is empirically known about the intersection between dying and aging as a felt experience of human finiteness and to describe the nature of the evidence (Tricco et al., 2018). Our review enabled us to summarize the basic findings and to identify gaps in the current approach to the research on this topic.

Our review found that there were only 5 empirical studies in the last 10 years that specifically focused on the idea of existential aging and dying as an identity issue whilst growing old. However, other studies worked in closely allied areas that explored how self-concepts of older people were influenced by the idea of death either as self-concerns about the inevitability of death (mortality salience), self-concerns about the prospect of death (death anxiety), attitudes toward the older self as a moderator of attitudes to death (aging attitudes), or simply anticipating the death of self (the future). All of these studies were from behavioral sciences. Although there are many studies that examine ‘death & dying’ in the social sciences, and particularly human development, most of these studies are cancer-related or palliative care-related. Few studies examine the dying experience in aging and those that do so, emphasize death preparation, planning, or ideas. No studies were found that explicitly investigated specifically how advancing age itself influenced one’s identity.

Collectively, the current studies found that death and dying were threats or challenges to an existing aging identity and that challenge requires compensation or accommodation within the self. These studies confirm the importance of nearness-to-death on identity formation and psychological change, and that fear of death appears widespread. However, often this fear was more specifically fear about particular aspects of death and dying and these were not uniform. Negative self-images of aging appear to court poor outcomes for physical and mental health. The link between seeking wider meanings in spirituality, social networks, or health maintenance, and a more positive sense of self despite nearness-to-death, supports the earlier empirical and theoretical work in both gerontology and thanatology. Finally, planning for death – and therefore a sense of a possible future – was more likely to occur in older people with better health. The more able bodied and less cognitively impaired were more likely to be able to entertain and articulate their concerns about death or dying.

The strength of the current studies has been their ability to confirm the emergent identity of dying in old age from across a wide array of similarly industrialized countries and utilize a wide array of surveys and scales underpinned by some strong, prior, theoretical work, mostly derived from psychoanalytic sources. The emergent identity of dying and the related association between attitudes towards existential aging and death, existential aging and finitude, or existential aging and anticipation of death is confirmed in both community-dwelling and care home populations. Finally, there is wide recognition of how diversity of

perceptions about death and dying by older people are dependent on their other experiences of physical and mental health, residential setting, gender, and support networks.

However, the limitations of these studies have been equally important to note. Top-down, quantitative, hypothesis-testing approaches have mostly produced negative, defensive, or narrow descriptions of aging and dying. On the other hand, the inductively-inclined, qualitative studies have been limited by their reliance on talk, marginalizing or omitting data from elsewhere, or by other means, that might suggest other forms of awareness of dying detected (or not) solely by means of talk. There has been a singular lack of mixed method approaches to this important topic. A lack of longitudinal studies, mixed methods studies in general, innovative mixed methods qualitative studies in particular, and studies from people whose experience is not best captured through reading or writing, has limited the current international understanding of the emergent identity of dying in old age. This highlights one final observation. International studies are not easily compared when there is little or no discussion of culture. While the experience or attitudes of the elderly in Israel or India is of interest in their own national terms there are limitations to any comparative insights if the cultural basis of those experiences are not made explicit in the studies themselves. This makes meaningful international comparison difficult, creating challenges to distinguishing existential psychology from culture-specific experience from one country to another. The lack of anthropological studies compounds this limitation on this topic.

The current need, and the promising future, belongs to studies that are more willing to take an inductive, qualitative approach to data collection, seeking to describe personal experience and to characterize that experience into themes. Inside that effort to understand the different threads of experience must be a move away from a reliance on talk-only methods and to seek corroboration and challenge from alternative sources and methods, particularly from observational methods but also existing sources such as letters, dairies, and other correspondence. There is a need for more longitudinal studies to recognize and to describe the evolving way dying as a new and perhaps final identity makes its way into an older life. Finally, it will be crucial for future studies to create, access, or partner with other researchers in countries or cultures that do not privilege talk. A mixed methods approach to future research will develop our understanding of aging and mortality with culture-specific sensitivities that are inclusive of the diversity within our global human experience.

## 6. Conclusion

There is a paucity of studies examining the intersections of dying and existential aging specifically as a felt experience linked to the sense of finiteness as the years advance in aging. There is a preponderance of studies linking the multimorbidity experiences of aging to a sense of dying, or impending death, but few that specifically examine how aging identity is shaped by a sense of impending death outside illness contexts. We reviewed 24 studies that explored this particular intersection of existential aging and the emergent identity of dying and found that most of them were quantitative or assumed problem or threat-based attitudes to death. However, there was also sufficient evidence from these studies to demonstrate that a sense of death or dying can emerge from 'healthy' populations, and be prompted by changes in social settings, gender and or support networks. This strongly suggests the need for future work to explore these 'non-illness/non-morbidity' factors as influences on an emergent identity in old age that goes beyond, or at least parallels the experience of the multimorbidity of aging and dying experience. For this work to clearly identify these and other social factors, more qualitative, sociological, and anthropological perspectives and studies will be essential. The sociological works of Kellehear (2007, 2014, 2020), Small et al. (2007), Walter (2020) or Caswell (2022), for examples - all works that examine aging and dying as an evolving social identity - could provide useful starting points for these kinds of studies in the future. For

if we are to free ourselves of reductionist ideas about dying linked solely to illness or frailty, seeing our confrontation with death in a more complex and nuanced way will require that our psychological insights are matched with those of the context sciences of sociology, anthropology, cultural studies, and social history.

## Funding

This research did not receive any specific grant from funding agencies in the public, commercial, or not-for-profit sectors.

## Data availability statement

Details of reviewed articles are available from the corresponding author upon reasonable request.

## Ethics approval and consent to participate

Not applicable.

## Consent for publication

Not applicable.

## CRediT authorship contribution statement

**Allan Kellehear:** Conceptualization, Methodology, Investigation, Writing – original draft, Visualization, Supervision, Writing – review & editing. **Matilda Garrido:** Methodology, Investigation, Writing – original draft, Methodology, Writing – review & editing.

## Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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