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#### ARTICLE



# A scoping review exploring the 'grey area' of suicide-related expression in later life: Developing a conceptual framework for professional engagement

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#### Abstract

As the body of research on suicide in later life has developed, so has its vocabulary. This has generated a high level of overlap in concepts and terminology used to articulate suicide and how it might present, as well as 'grey area' behavioural terms that are both specific to older adults and less well-defined (e.g. 'hastening of death' or 'completed life'). A better understanding of individual experiences and pathways to suicide can help to inform assessment and interventions, and increase the potential to relate any theoretical concepts to the implementation of such. Here, we adopted a scoping review to search systematically literature on specific presentation, features, circumstances and outcomes of these grey areas of suicide in later life. Fifty-three articles (quantitative, qualitative and theoretical) were reviewed. A narrative approach was used to merge and translate this body of knowledge into a new conceptual framework based on four key themes: (a) a sense of completed life or existential loneliness; (b) death thoughts, wishes and ideation; (c) death-hastening behaviour and advanced directives; and (d) self-destructive or self-injurious behaviour. We discuss the importance of integrating this understanding into current knowledge and suicide prevention strategies for older adults. Recommendations are made for unifying research with policy themes on healthy ageing, person-centredness within service provision and citizen participation.

Keywords: ageing; older adults; suicide; scoping review; conceptual framework; wish to die

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#### Introduction

Nearly 800,000 people die by suicide every year (World Health Organization (WHO), 2019). Some of the highest rates of suicide worldwide are recorded in older adults (per 100,000 individuals), in part due to the growing ageing population (United Nations, 2019). For example, worldwide suicide rates were over twice as high in those aged 70+ (27.8 per 100,000) compared to those aged 15-49 (11.73 per 100,000) in 2015 (Ritchie et al., 2015). It should, however, be noted that rates of suicide in later life do differ across cultural, political and sociological contexts: suicide rates among older people are relatively low in the global South but much higher in the global North compared with younger populations (Nock et al., 2008; Stanley et al., 2016). These increased rates of suicide only appear to decline after the age of 95 for men and the age of 90 for women (Shah et al., 2016), and across the European Union, deaths by suicide are four to five times higher in men than women (Freeman et al., 2017). The United Nations and WHO Sustainable Development Goals have prioritised a co-ordinated response to suicide prevention (United Nations, 2015; WHO, 2019). However, suicide in later life represents an increasing challenge for public health, given the many complexities in how it is conceptualised, theorised, recognised and responded to (Van Orden and Conwell, 2011).

Research on suicide and related behaviours among older adults has highlighted a high level of overlap in concepts and terminology, as well as gaps in our understanding (Conejero et al., 2018). Risk factors for suicide ideation and suicide-related behaviours in older adults are multifaceted and include: gender (Morgan et al., 2018), age (Conwell et al., 1998), mental ill health (particularly major depression) (Conwell et al., 1996), stressful life events (Van Orden and Conwell, 2011), loneliness or limited social connectedness (Fässberg et al., 2012; Wand et al., 2018), problematic substance use (Kuerbis et al., 2014) and physical illness or functional impairment (Erlangsen et al., 2015; Fässberg et al., 2016). The US National Violent Death Reporting System data show that the most salient precipitating factor was the known presence of health problems and the absence of standard markers of suicidality (Centers for Disease Control and Prevention, nd). These contributory factors further highlight the complexity of identifying the breadth of suicide-related behaviours in later life, as well as the need to advance our understanding of how these are expressed.

The vocabulary and disaggregation of suicide and suicide-related concepts in older people include a range of 'grey area' behaviours (for lack of a better term), that are either less common, or present differently, than in younger population groups. These include terms and behaviours such as 'completed life', 'hastening of death' and 'self-chosen death' (Monforte-Royo *et al.*, 2011; van Wijngaarden *et al.*, 2016a). Expression of these grey area behaviours may also be mistakenly viewed as a 'normal' part of ageing (Balasubramaniam, 2018), creating further complexity to their identification and subsequent intervention. Bridging this implied knowledge-to-practice gap by enhancing understanding of the full breadth of suicide-related expression in later life will be useful for suicide prevention theorists and professionals working directly with older people. The primary aim of this present work is to thus develop a conceptual framework that accounts for this *grey area* of suicide in older adults.

In their seminal review of suicide in later life, Van Orden and Conwell (2011) identified the lack of theory-driven research within this area. Translating theoretical knowledge to applied problems and contexts is a complex, multi-step process that consists of exchanging, synthesising and applying research findings to practice settings (Hudon et al., 2015). Conceptual frameworks are an important step in this process. They consist of a set of linked concepts designed to highlight a phenomenon of interest that can help organise thinking and guide the choice of suitable implementation strategies (Hudon et al., 2015; Kafri and Atun-Einy, 2019). Previous systematic and literature reviews exploring ageing and suicide have examined the prevalence, risk factors and characteristics of self-harm (Wand et al., 2018; Troya et al., 2019), self-injurious behaviour (Mahgoub et al., 2011) and suicidal intentions (Diehl-Schmid et al., 2017), as well as the role of social factors (Chang et al., 2017) in suicidal behaviour. Existing topics of these reviews have been approached from broad perspectives. For example, Stanley et al. (2016) comprehensively reviewed key extant psychological and sociological theories of suicide, discussing each theory's applicability to the understanding and prevention of suicide among older adults. Others have conducted reviews from sociological perspectives, exploring the social determinants of health related to suicide in later life (Carvalho et al., 2020), and the impact of socio-economic status (Ju et al., 2016), living environments (Li and Katikireddi, 2019; Dautovich et al., 2021) and gender (Canetto, 1992; Heisel et al., 2020) on suicide and related behaviours in later life. Building on this existing knowledge base, the present work adopts a systematic scoping review approach to develop a conceptual framework that describes the grey areas of ageing and suicide; with a view to articulating (a) how these behaviours are expressed/present themselves, (b) the risk factors in their development, and (c) how formal conceptualisation might frame a realm for engagement with older adults towards a better understanding of what informs suicide prevention and interventions.

#### **Methods**

This research adopted a scoping review methodology (Arksey and O'Malley, 2005; Munn et al., 2018) to search the body of literature, map and review the state of research evidence, and identify knowledge gaps. The decision to adopt a scoping of studies framework emerged from an initial inspection of the key sources in the body of work, also taking account of existing reviews such as those mentioned earlier and their theoretical focus. Scoping reviews are suitable for addressing broad, rather than narrow or specific, research questions, and to incorporate a range of different study designs (rather than restricting inclusion to only empirical quantitative research). We followed a systematic approach for study identification and selection, and adopted a narrative approach when extracting, charting and synthesising the relevant data in order to best capture and articulate the relevant concepts and to examine how research has been conducted on this topic. Due to the broad range of methodologies used in the articles included in this review, we adopted a narrative approach to describe the data. The narrative approach adopted to present the results provided a more comprehensive, critical and objective analysis of the current knowledge to help establish a theoretical framework (Munn et al., 2018).

#### Stage 1: Identifying the research questions

The initial stages of this research were explorative, and we began by asking the following research questions:

- (1) What type of research has been conducted in this field?
- (2) What can the literature tell us about the specific presentation, features, circumstances and outcomes of suicide-related behaviour and expressions unique to later life, particularly what the 'grey areas' are; and how are these conceptualised and theorised?
- (3) How might we merge and translate this body of knowledge into an accessible conceptual framework, and how may this facilitate an infrastructure for suicide prevention and help identify gaps in knowledge for practice?

#### Stage 2: Identifying relevant sources

We then conducted several pilot searches to identify all appropriate search terms for these grey areas (or 'fringe terms'). Candidate terms were generated based on the researchers' own knowledge of the field and key works, and the subject terms of major literature databases. The results of the pilot searches were discussed between team members and the final set of search terms were agreed.

Systematic searches of five major literature databases were completed between July and August 2020 (by TE) using the following search terms: 'Older adult' OR 'Older people' OR 'Elderly' OR 'Geriatric' OR 'Ag?ing' OR 'Dementia' OR 'Palliative' AND 'No longer wishing to live' OR 'Giving up' OR 'Death wishes' OR 'Death ideation' OR 'Self-neglect' OR 'Self-destructive behavio?r' OR 'Self-chosen death' OR 'Hastening of death' OR 'Completed life' OR 'Death fastening' OR 'Voluntary stopping of eating and drinking'. This returned the following results: Web of Science (266 results), Scopus (403 results), PubMed (212 results), Social Care Online (291 results) and PsychInfo (527 results). Once duplicates had been removed, the search produced 1,107 results (Figure 1).

Articles were eligible for inclusion if they were published in peer-reviewed journals between January 2010 and June 2020, focused on older adults (60 years and above), explored any aspect of 'grey area' suicide-related behaviour and were published in the English language. The rationale for the study period was based on the publication of two key reports from the WHO (2014, 2015). These reports, and the lead-in period preceding their publication marked an increase in attention directed to the field of ageing and suicide.

Two authors (CR and TE) screened the 1,107 abstracts against the above inclusion criteria. Three authors (THL, BJ and TE) reviewed the 138 papers at the full-text stage, resulting in the inclusion of 45 articles. Any disagreements were discussed through critical dialogue with all authors. A small number of sources were further identified from either the reference list of included articles or by colleagues with expertise of the research area (N=8). The final number of peer-reviewed sources included in the review was 53.

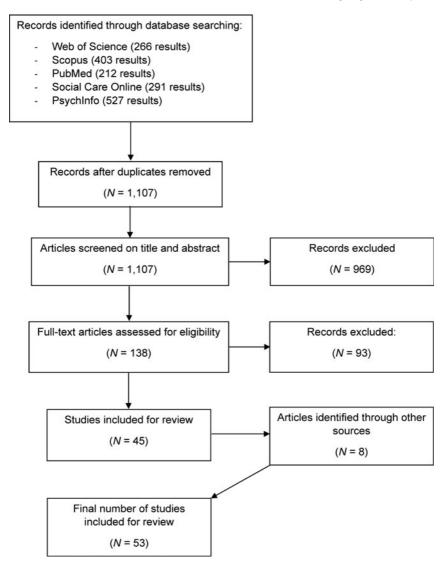


Figure 1. PRISMA flow diagram.

#### Stage 3: Data charting

We abstracted a standardised set of information from each included source: author information, type of source (and, for experimental papers, the methodologies used and population studied), concepts used/explored and key findings. The data were recorded and stored in an Excel spreadsheet. The abstracted data were separated into four separate tables according to key concept explored (*see* Tables 1–4).

 Table 1. The articles included in the scoping review that primarily investigated topics from Concept 1 (completed life, tired of life, existential loneliness)

Authors (year)	Study design/ type	Participants	Topic/s of study	'Grey area' concept/s
Bolmsjö <i>et al.</i> (2019)	Review	N/A	To clarify what constitutes existential loneliness, and to identify how this differentiates from other kinds of loneliness	Existential loneliness
Hafford-Letchfield et al. (2020)	Qualitative (focus groups)	Staff members (N = 33) working in English care homes for older people (including care home managers, deputy managers and care workers)	To explore the concept of 'giving up' from the perspective of staff working in care homes	Giving up; refusing care; wish to die
Kjølseth <i>et al.</i> (2010)	Qualitative (interviews)	Informants (N = 63; relatives, medical practitioners and social workers) who had personal experience with suicide in a person aged over 65 (23 total cases of suicide across the sample)	To explore how older people who have completed suicide experienced their life in the period of time before they died	Tired of living; 'No life left'; no desire to live; wish to die
Richards (2017)	Review/ opinion	N/A	To discuss the key issues relating to old age 'rational suicide' and the notion of 'a completed life'	Completed life; rationale suicide
van Wijngaarden et <i>al</i> . (2015)	Qualitative (interviews)	Dutch people aged 70+, who viewed their life to be 'completed' and no longer worth living, and who strongly wished to die while not being terminally or mentally ill (N = 25; mean age = 82; female = 56%)	To describe the phenomenon 'life is completed and no longer worth living', as it is lived and experienced by elderly people	Giving up; completed life; wish to die

van Wijngaarden et al. (2016a)	Qualitative (interviews)	Dutch people aged 70+, who viewed their life to be 'completed' and no longer worth living, and who strongly wished to die while not being terminally or mentally ill (N = 25; mean age = 82; female = 56%)	To explore what it means to live with the intention to end life at a self-chosen moment	Completed life; self-chosen death ideation; self-chosen death wish; wish to die
van Wijngaarden et al. (2018)	Opinion/ theory	N/A	Exploring empirical evidence of the lived experience of older people who consider their lives to be completed and no longer worth living, and to analyse the emerging social and political challenges behind the wish to die	Completed life; wish to die

Notes: Whilst some articles investigated topics across multiple concepts, they are grouped here based on the primary topic/concept of study. N/A: not applicable.

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Table 2. The articles included in the scoping review that primarily investigated topics from Concept 2 (wish to die, death wishes, thoughts of death, death ideation, self-chosen death)

Authors (year)	Study design/type	Participants	Topic/s of study	'Grey area' concept/s
Ayalon and Shiovitz-Ezra (2011)	Longitudinal (predictive) questionnaire study	European older people aged 66–75 (N = 2,891; female = 54%) and 75+ (N = 1,503; female = 65%)	The relationship between loneliness and passive death wishes	Passive death wishes
Bernier <i>et al.</i> (2020)	Cross-sectional (questionnaire) study	Canadian older people (N = 2,787; mean age = 74; female = 59%)	The relationship between social interactions and a wish for death	Wish for death
Bonnewyn <i>et al.</i> (2014)	Cross-sectional (questionnaire) study	Belgian older people who were psychiatric or somatic inpatients (N = 113; mean age = 74; female = 54%)	Life factors associated with a wish to die	Wish to die
Bonnewyn <i>et al.</i> (2016)	Cross-sectional (questionnaire) study	Belgian older people who were psychiatric or somatic inpatients (N = 113; mean age = 74; female = 54%)	The relationship between attitudes towards death and a wish to die	Wish to die
Briggs <i>et al</i> . (2018)	Cross-sectional (questionnaire) study	Irish older people aged 65–74 (N = 2,043; mean age = 69; female = 53%) and 75+ (N = 1,250; mean age = 80; female = 53%)	The prevalence of death ideation	Death ideation
Cavalcante and Minayo (2015)	Qualitative (interviews)	Brazilian older people at risk of suicide (N = 60; 50% of participants aged 60–69; 30% aged 70–79; 20% aged 80+; female = 59%)	To provide examples of suicidogenic crises, the role of ambivalence between wanting to live and wishing to die, the relational aspects of suicidal behaviour and normal thoughts about death	Wish to die; suicide and death ideations
Cheung <i>et al</i> . (2017)	Cross-sectional study (questionnaires and social care assessment)	Older New Zealanders receiving home-based social support (N = 35,734; mean age = 82; female = 61%)	The prevalence and predictors of death wishes	Death wishes
				Death ideation

Table 2. (Continued.)

Authors (year)	Study design/type	Participants	Topic/s of study	'Grey area' concept/s
Kjølseth and Ekeberg (2012)	Qualitative (interviews)	Informants (N = 63; relatives, medical practitioners and social workers) who had personal experience with suicide in a person aged over 65 (23 cases of suicide across the sample)	To investigate if, when and how older people give warning prior to suicide; and how these warnings were perceived by the recipient	Wish to die
Lapierre et al. (2012)	Cross-sectional (questionnaire) study	French-speaking Canadian older people (N = 2,777; mean age = 74; female = 59%)	The prevalence and health predictors (illnesses, sleep quality, number of daily hassles) of a wish to die	Wish to die
Lapierre <i>et al.</i> (2015)	Cross-sectional (questionnaire) study	French-speaking Canadian older people (N = 2,811; mean age = 74; female = 70%)	Medical problems associated with a wish to die	Wish to die
O'Riley <i>et al</i> . (2014)	Cross-sectional (questionnaire) study	American older people accessing social support services (N = 377; mean age = 77; female = 68%)	Prevalence of death ideation and possible associated factors (depression, anxiety, alcohol misuse)	Death ideation; wish to die
Park et al. (2013)	Cross-sectional (questionnaire) study	Korean older people (N = 848; mean age = 71; female = 60%)	Prevalence of suicide ideation with, and without, a plan – explored in relation to gender and age	Suicide ideation with, and without, a plan
Raue <i>et al.</i> (2010)	Cross-sectional (questionnaire) study	American older people (N = 1,202) separated into those with no depression (N = 610; mean age = 72; female = 69%), minor depression (N = 200; mean age = 72; female = 71%) and major depression (N = 379; mean age = 70; female = 73%)	The effects of a wish to die on mortality status over a 5-year period	Wish to die
Rurup <i>et al</i> . (2011)	Qualitative (interviews)	Dutch older people (N = 31; mean age = 74; female = 58%)	To understand why some older people develop a wish to die	Wish to die

Stolz <i>et al</i> . (2016)	Longitudinal (questionnaire) study	Older people (N = 6,791; mean age = 81; female = 58%) collected via SHARE (data collected in 12 European countries)	Prevalence of passive suicide ideation assessed at two time-points (approximately 2 years apart). Individual and cultural predictors of passive ideation also explored	Passive suicide ideation
Van Orden and Conwell (2016)	Opinion	N/A	Exploring whether thoughts of death are a normative part of nearing end of life or an indicator of suicide risk, and whether wishing for death in later life is an indicator of suicide risk or merely an indicator of weariness with life	Death ideation; wish for death
Van Orden <i>et al</i> . (2013)	Cross-sectional (questionnaire) study	Swedish older people (N = 345; all participants aged 85; female = 70%)	The relationship between death ideation and markers of an elevated risk of suicide	Death ideation
Van Orden <i>et al.</i> (2015)	Cross-sectional (questionnaire) study	American older people seeking age-related social services (N = 377; mean age = 77; female = 68%)	The relationship between passive and active suicide ideation, and psychological distress	Passive and active suicide ideation
van Wijngaarden et al. (2016b)	Opinion/theory	N/A	To evaluate research that has investigated death wishes among older people and the concept of disconnectedness	Death wishes
van Wijngaarden et al. (2019)	Qualitative (interviews)	Dutch people aged 70+, who viewed their life to be 'completed' and no longer worth living, and who strongly wished to die while not being terminally or mentally ill (N = 25; mean age = 82; female = 56%)	An exploration of the use and meaning of metaphors and images about ageing in older people with a death wish, in an attempt to elucidate what these tell us about their self-understanding and imagined feared future	Wish to die

Notes: Whilst some articles investigated topics across multiple concepts, they are grouped here based on the primary topic/concept of study. N/A: not applicable. UK: United Kingdom. SHARE: Survey of Health, Ageing and Retirement in Europe.

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**Table 3.** The articles included in the scoping review that primarily investigated topics from Concept 3 (voluntary stopping of eating and drinking (VSED), death hastening, advanced directives)

Authors (year)	Study design/type	Participants	Topic/s of study	'Grey area' concept/s
Bolt <i>et al.</i> (2015)	Survey	Dutch family physicians (N = 708)	The role that family physicians play when a patient deliberately hastens death through VSED	Hastening of death; VSED
Kohlhase (2016)	Opinion/case study	N/A  Describes a case study of an 81-year-old patient who was not actively suicidal but had voluntarily stopped eating and drinking as she felt she had 'lived long enough'		VSED; advance directives
Monforte-Royo et al. (2011)	Systematic review	N/A	A systematic review of the current state of knowledge about the wish to hasten death among people with end-stage disease (including – but not restricted to – older people)	Wish to hasten death; wish to die
Rodríguez-Prat et al. (2018)	Review/opinion	N/A	A discussion on the ethical challenges for understanding suffering in the context of VSED and a wish to hasten death	VSED; wish to hasten death
Stängle <i>et al</i> . (2019)	Qualitative (interviews)	Eighteen relatives of people who had died through VSED in Switzerland (including both those older and younger than 60)	To explore the different forms of VSED (e.g. expression of disease <i>versus</i> explicit wish to die)	VSED; wish to die
Stängle <i>et al</i> . (2020)	Cross-sectional (questionnaire) study	Heads of Swiss nursing homes (N = 535)	Nursing home staff's attitudes and experiences with VSED	VSED
Steinbock and Menzel (2018)	Opinion/theory	N/A	A discussion surrounding how to create effective advance directives in those withing to avoid living into severe dementia	Advance directives
Trowse (2020)	Review/theory	N/A	Analysis of Australian legislation, Australian case law and journal articles exploring the ethical and legal validity of advance directives that request the VSED against a backdrop of late-stage dementia	VSED; advance directives
Wax et al. (2018)	Opinion	N/A	To provide a review of ethical and legal considerations of VSED	VSED

Notes: Whilst some articles investigated topics across multiple concepts, they are grouped here based on the primary topic/concept of study. N/A: not applicable.

Table 4. The articles included in the scoping review that primarily investigated topics from Concept 4 (self-destructive or self-injurious behaviour)

Authors (year)	Study design/type	Participants	Topic/s of study	'Grey area' concept/s
Burnett <i>et al</i> . (2014)	Analysis of social service records	5,686 cases of investigated self-neglect in American older people (mean age = 77; female = 64%)	The different sub-types of self-neglect that exist in older people	Self-neglect
Charles <i>et al</i> . (2015)	Longitudinal study (using questionnaires to predict medical outcome)	Cognitively impaired Canadian older people (N = 224; mean age = 84; female = 85%)	Does depression or quality of life predict harm due to self-neglect?	Harm from self-neglect
Dong <i>et al</i> . (2017)	Cross-sectional (questionnaire) study	Chinese-American older people (N = 3,159; mean age = 73; female = 58%)	The relationship between self-neglect and suicide ideation	Self-neglect; wish to be dead
Ekramzadeh et al. (2012)	Cross-sectional (questionnaire) study	Iranian older people attending hospital services (N = 570; mean age = 71; female = 40%)	The relationship between self-destructive behaviours and suicide (and death) ideation	Self-destructive behaviours; death ideation
Mahgoub <i>et al</i> . (2011)	Review	N/A	A review of the existing literature on self-injurious behaviour (defined as harm inflicted on oneself without conscious suicidal intent) among older people living in nursing homes	Self-injurious behaviour
Morgan <i>et al</i> . (2018)	Analysis of primary medical records	Medical records of UK older people with a self-harm incident (N = 4,124; 42% aged 65–74; 37% aged 75–84; 21% aged 85+; female = 58%)	The incidence of self-harm in older people; and the relationship between self-harm incidents and subsequent likelihood of unexplained death or suicide	Self-harm

(Continued)

Table 4. (Continued.)

Authors (year)	Study design/type	Participants	Topic/s of study	'Grey area' concept/s
Shah and Erlangsen (2014)	Opinion/editorial	N/A	A discussion surrounding the concepts of passive/hidden suicide, indirect self-destructive behaviours, and a wish to die	Indirect self-destructive behaviours; passive/ hidden suicide; wish to die
Wand <i>et al</i> . (2018)	Systematic review	N/A	A systematic review of qualitive studies researching self-harm among older people; specifically, the reasons why older people self-harm	Self-harm

Notes: Whilst some articles investigated topics across multiple concepts, they are grouped here based on the primary topic/concept of study. N/A: not applicable. UK: United Kingdom.

Concept	Quantitative	Qualitative	Review/ theory	Total
1. Completed life, tired of life, existential loneliness	0	4	3	7
2. Wish to die, death wishes, thoughts of death, death ideation, self-chosen death	23	9	6	38
3. Voluntary stopping of eating and drinking, death hastening, advanced directives	2	1	6	9
4. Self-destructive or self-injurious behaviour	5	0	3	8

Table 5. Number of articles included in each concept, separated by article type

Note: As some articles focused on more than one primary concept, the total sum is greater than the total number of included articles.

#### Stage 4: Collating, summarising and reporting the results

We then provided a narrative account of the included studies. Throughout the process of charting the data, common themes were identified by the authors. The main findings and key concepts studied are organised thematically, according to the following four sub-concepts: (a) completed life and existential loneliness; (b) death wishes, thoughts and ideation; (c) death-hastening behaviours and advanced directives; and (d) self-destructive or self-injurious behaviours (see Table 5).

#### Results

#### Overview of the literature reviewed

8 of the 53 articles reviewed, the large majority were empirical (39 articles) and used quantitative methods (29 articles). The other ten empirical articles adopted qualitative methods (8 articles used interviews whilst two used focus groups). The remaining 14 articles were classified as review/theory pieces, and included systematic reviews (2 articles), narrative reviews (4 articles), theoretical discussions (1 article) and opinion 'think pieces' (7 articles). The included articles most commonly emanated from either the United States of America (14 articles) or the Netherlands (7 articles).

Most empirical articles collected data amongst older people themselves (32 articles); whilst seven studied either family members of older people or health-care practitioners with experience of the concept studied. Of the empirical articles that collected data in older people (32 articles), the sample sizes ranged from 25 to 35,723 participants. Most of these (30 of 32 articles) included samples that were made up of majority female participants (range from 53 to 85% of participants studied). The mean ages of the older adult participants studied ranged from to 71 to 97 years (although some studies did not report means for the total sample, but rather subsets of the sample), with most articles (21 of 32) reporting mean ages of 80 years or younger. All but one article (Charles *et al.*, 2015) studied older people

without cognitive impairment, and only four articles studied those in inpatient facilities. One article (Raue *et al.*, 2010) explored the effects of a multimodal intervention (anti-depressants and interpersonal Psychotherapy).

Table 5 above shows the sum of articles covering each of for key concepts, separated by article type.

The four concepts were explored in: 7 articles (Concept 1: completed life, tired of life, existential loneliness), 38 articles (Concept 2: wish to die, death wishes, thoughts of death, death ideation, self-chosen death), 8 articles (Concept 3: voluntary stopping of eating and drinking, death hastening, advanced directives) and 9 articles (Concept 4: self-destructive or self-injurious behaviour), respectively (*see* Table 5). The majority of articles that studied Concept 1 topics used qualitative methods (4 of 7 articles), whilst the majority of articles that explored both Concept 2 (23 of 38 articles) and Concept 4 (5 of 8 articles) used quantitative methods. Finally, Concept 3 topics were primarily explored through review/theory pieces (6 of 9 articles).

#### **Concept 1: Completed life and existential loneliness**

Richards (2017) and van Wijngaarden *et al.* (2016a, 2018) studied the more abstract notion of a 'completed life' for older people. Both articles describe completed life as occurring where the older adult expresses a sense of feeling unable or unwilling to connect with actual life. This notion of disconnectedness constitutes five aspects including (a) a sense of aching loneliness, (b) the pain of not mattering, (c) the inability to express oneself, (d) physical tiredness and/or existential boredom, and (e) a sense of aversion towards feared dependence (Richards, 2017). In a retrospective study consulting people close to an older person who had completed suicide (Kjølseth *et al.*, 2010), existential experiences involving anxiety about a future that would entail further loss of self-determination and self-sufficiency were frequently expressed by the older person. They spoke of a life that has been lived and life as a burden, particularly where there was a loss of something they had enjoyed doing or feeling, a loss of value, a feeling of tiredness and, in some cases, a feeling that they were in a process of losing themselves.

Existential loneliness differentiated from other types of loneliness according to Bolmsjö *et al.* (2019). Those describing it identified an awareness of being fundamentally separated from other people and of one's own mortality. The synthesis of studies by Bolmsjö *et al.* (2019) revealed that where people's needs were not being met (typically in a crisis), or where they lacked connection or communication at a deep human or authentic level, their experiences were often associated with negative feelings, emotion or moods. These included sadness, hopelessness, grief, meaningless and anguish. These experiences were discussed by some authors in the context of the assisted dying movement (Richards, 2017; van Wijngaarden *et al.*, 2018). These articles highlight the rational features of suicide ideation or planning for suicide, describing how this is at least partly driven by societal factors such as marginalisation and negative stigma associated with later life.

#### Concept 2: Death wishes, thoughts and ideation

The prevalence of death wishes, thoughts and ideation varied across the individual studies, with between 3 per cent (Briggs et al., 2018) and 26 per cent of older people

reporting these (Fässberg et al., 2013). These values appeared to vary based on how death wishes were determined (e.g. current wishes to die versus a wish to die at some point in the previous month). Monforte-Royo et al. (2011) highlighted the lack of terminological and conceptual precision in defining this construct, highlighting the need to distinguish between a generic wish to die, the explicit expression of a wish to die, and a request for euthanasia or physician-assisted suicide. These authors further differentiate these concepts between thoughts, wishes and intentions, implying progressively greater proximity to actual death.

Raue *et al.* (2010) found that whilst higher rates of a wish to die were reported in depressed older adults (reported in 29% of participants with major depression and 11% of participants with minor depression), similar wishes were also reported by 7 per cent of older people without depression. That a wish to die can occur independently from depression in older people was further supported by research conducted by Fässberg *et al.* (2013) in their study of 269 very old Swedish people without dementia (all participants aged 97). Whilst approximately one-quarter (26%) of participants reported thinking about their own death at least once per month, only 11 per cent reported actually wishing for death ('Have you ever wished you were dead, for instance, that you could go to sleep and not wake up?'). Most of these participants (77.4%) fulfilled criteria for neither major nor minor depression.

A wish to die does not, however, appear to be a 'normative' part of ageing. Van Orden *et al.* (2015) explored the relationship between passive and active death ideation, and psychological distress, in a cohort of 377 American older people seeking age-related social services (mean age = 77 years; female = 68%). As their results indicated that passive ideation rarely presents in the absence of significant risk factors for suicide (*i.e.* psychological distress or active ideation), the authors concluded that a passive desire for death does not appear to be normative in late life. Indeed, a wish to die was significantly associated with increased mortality rates over a five-year period in older people without depression (Raue *et al.*, 2010). Interestingly, a wish to die was not associated with increased mortality in those who received a multimodal intervention (anti-depressants and Interpersonal Psychotherapy), and Raue *et al.* (2010) suggest that this may be a fruitful avenue for developing future interventions.

The included empirical quantitative articles related to this concept paint a complex picture regarding the explored factors associated with developing a wish to die. These include: perceived loneliness (Ayalon and Shiovitz-Ezra, 2011; Stolz *et al.*, 2016; Cheung *et al.*, 2017), burdensomeness and hopelessness (Cukrowicz *et al.*, 2013; Guidry and Cukrowicz, 2016), a dissatisfaction in one's social life (Stolz *et al.*, 2016; Bernier *et al.*, 2020), feeling distant towards others (Bernier *et al.*, 2020), viewing one's life as having no purpose (Bonnewyn *et al.*, 2014), perceived lack of control over one's life (Bonnewyn *et al.*, 2014; Stolz *et al.*, 2016) and functional disability (Fässberg *et al.*, 2014).

The empirical qualitative articles related to this concept provide further insight into the development and expression of a wish to die in later life. Cavalcante and Minayo (2015) categorised the precipitating and associated factors about wish to die into four areas. These covered: (a) depression as an illness or associated with losses; (b) suffering as a result of chronic or painful diseases and functional incapacities; (c) abuse of alcohol and other drugs; and (4) personal experience of

violence, and abandonment during the lifecycle. These findings suggest that wish to die by suicide was expressed in highly complex ways, and occurred following some form of loss including accidents, violence, sickness, financial, the abuse of alcohol and other drugs, and mental disturbances. It was reported that these lifecourse events ran through childhood, adolescence and adult life, and the experiences evoked affective, social problems and rifts that similarly ran through the older person's lifecourse. The pain of not mattering, feeling marginalised and sidelined, not being able to make a meaningful contribution and not being taken seriously, was described as 'a tangle of inability to connect with one's own actual life' (van Wijngaarden *et al.*, 2015: 262).

Rurup et al. (2011) used their qualitative data to develop a framework to describe the origination and development of the wish to die. In addition to describing the life events and/or problems that were the original trigger in the development of the wish to die, other risk factors included becoming dependent and experiencing sensory loss linked to external factors, such as the perceived burden of ageing on society. Similar to findings by Kjølseth et al. (2010), some older people with a wish to die specifically described the hurt caused from the lack of interest of their children despite asking them for support. Rurup et al. (2011) also found recurring themes related to personal character, coping strategies and social support that played a role in the way the respondents dealt with these events or situations. They articulate four dynamic aspects of negative and positive sides of living and dying which formed a balance of feelings towards living and dying. Where this balance was stabilised, some people expressed a wish to die, but not to complete suicide. Most, however, experienced this balance as less stable. The anticipation of losing something positive in their life, such as a loved one or their independence, made them less sure what they would do at that point or to a decision to end their life. The 'in-betweenness' of intending and actually performing self-directed death (or not) was also characterised as a constant feeling of being torn. van Wijngaarden et al. (2016b) described these paired themes as follows: (a) detachment and attachment; (b) rational and non-rational considerations; (c) taking control and lingering uncertainty; (d) resisting interference and longing for support; and (e) legitimacy and illegitimacy.

Kjølseth *et al.* (2010) suggest that establishing trust is essential to help people in existential situations that may lead to death wishes and ultimately the risk of suicide. This requires the time, ability and courage to take up such difficult subjects with them. What was clear in these studies was that in relation to wish to die, depression may or may not occur, and where symptoms are present, they formed part of a complex whole thus underlining the importance of a more holistic approach understanding how thoughts and feelings related to suicide in later life are expressed.

#### Concept 3: Death-hastening behaviours and advanced directives

Most of the included articles (seven) that explored death-hastening behaviours focused specifically on voluntary stopping of eating and drinking (VSED). As the term implies, VSED occurs when a person deliberately stops eating and drinking and is associated with the wish to hasten death. The debates within this body of literature draw on its ethical considerations (Rodríguez-Prat *et al.*, 2018; Wax *et al.*, 2018), particularly in the case of advanced directives – an issue made

more complex where the person is living with dementia (Steinbock and Menzel, 2018; Trowse, 2020).

Stängle *et al.* (2019) attempted to identify and distinguish between different forms of oral nutrition refusal and subtypes of VSED, to show a further awareness of different forms of nutrition refusal. They found that the decisive difference between refusing nutrition and VSED is that the former can occur as a result of illness, a specific condition or a lack of motivation to get better, whereas VSED constitutes an explicit desire to die often without the former. The exploration by Rodríguez-Prat *et al.* (2018) of the meaning of the wish to hasten death in patients with advanced disease concluded that VSED 'can be understood as a response to physical, psychological and/or spiritual suffering, as an expression of a loss of self, a desire to live but not in this way, a way of ending suffering, and as a kind of control over one's life'.

Kohlhase's (2016) case study of an 81-year-old patient engaging with VSED, however, challenged the potential for ambiguity in whether VSED is consistent with the wish to hasten death. Kohlhase described a patient who felt she had lived long enough but she also said that she did not want to die - despite understanding the consequences of VSED. The patient had a long-standing history of depression and refused medication. The hospital staff assessed that the patient was in her rights to continue VSED and transferred her to a hospice and prescribed medication for pain. The medication, however, was also an anti-depressant and as a result the patient began to eat more and eventually recovered. The authors illustrated how this case study demonstrated the complexities of understanding the interplay between individual wishes and intent to die, medical care practices and legislation, and the influence of depression on cognitive capacity for decisionmaking. The included articles exploring VSED highlight how prior to interpreting VSED as a deliberate expression of personal autonomy, it is important to explore all possible areas of suffering, including physical symptoms, psychological distress, existential suffering and social aspects.

It is important to consider the context when summarising the articles engaged with this concept, for example, in some of the countries in which the research originates, there are legal provisions for euthanasia. In one such country, a survey of Dutch family physicians (Bolt *et al.*, 2015) found that nearly half of them had cared for a patient who hastened death by VSED. These patients had a median age of 83 years, the majority of whom had a severe disease and were reliant on others for everyday care. The most significant reasons for patient VSED were somatic (79%) and existential suffering (77%). Most of these respondents (64%) felt that VSED is a natural death, whereas 26 per cent viewed it as passive euthanasia.

Staff in the study by Hafford-Letchfield *et al.* (2020) of 'giving up' in care homes in England described a sense of helplessness in not knowing what to do in response, thus highlighting tensions in providing the right support and creating spaces to respond to such challenging situations. Supporting instances where an older person seeks to hasten death requires skilled, detailed assessment to respond to risks alongside improved training and support for paid carers, to achieve a more holistic strategy, which capitalises on significant relationships within a wider context.

#### Concept 4: Self-destructive or self-injurious behaviours

The articles grouped here primarily investigated topics such as self-harm, indirect and direct self-destructive or self-injurious behaviour. Burnett *et al.* (2014) identified four unique subtypes of self-neglect in older people: (a) physical and medical neglect (occurring in 49% of cases), (b) environmental neglect (namely related to living conditions; 22% of cases), (c) global neglect (neglect in multiple domains; 21% of cases), and (d) financial neglect (9% of cases). They found that individuals presenting global neglect behaviours were more likely to be older and single, whilst those presenting financial neglect behaviours were more likely to be younger.

The included articles also highlighted a clear association between self-destructive behaviour – namely self-neglect – and both death wishes and suicide ideation. For example, Dong *et al.* (2017) observed higher levels of self-neglect were significantly associated with an increased risk of suicidal ideation. Relatedly, Ekramzadeh *et al.* (2012) explored the relationship between self-destructive behaviours and suicide/death ideation. Higher overall scores on the Beck Scale for Suicide Ideation (which assesses both death wishes and suicidal desires) were positively associated with greater self-destructive behaviour.

In a systematic review of the qualitative studies that explored self-harmful and destructive behaviours, Wand *et al.* (2018) presented findings that suggest that self-neglect should be conceptualised as a defensive behaviour that has maladaptive outcomes. They found that self-neglect was associated with attempts to regain control over personal freedom and/or living arrangements, or in response to threats to self-identity. Their findings also suggested that for some older people self-neglect may reflect impaired coping skills or cognitive impairment. Combined, the findings presented in this section suggest that self-destructive behaviours in later life can occur when an individual seeks to regain control following an event that has led to a wish to die.

#### Discussion

#### **Summary of findings**

The large majority ( $\sim$ 70%) of articles included in this review explored topics related to death wishes, thoughts and ideation (Concept 2). In contrast, few empirical studies explored the topics of either completed life and existential loneliness (Concept 1), or hastening of death and advance directives (Concept 3). Furthermore, none of the studies in this latter group were conducted in older people themselves (but rather family members of health-care professionals with experience of these topics). These research gaps substantially limit our understanding of these concepts and our ability to measure prevalence of the phenomena. Future research should seek to actively include older people themselves when investigating these topics and concepts.

Most empirical articles included in this review studied participants with a mean age of 80 years or younger. While some studies did focus on participants older than 80 (e.g. participants who were all aged 97 were studied by Fässberg et al. 2013), comparatively less is known about how (or even what) grey areas are expressed in older adults aged 80 and above. Relatedly, only one of the included articles studied older people with cognitive impairment, and most participants studied were also living independently in the community. There is similarly a lack of understanding

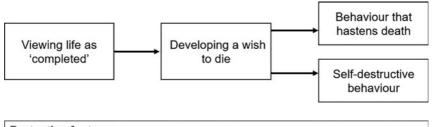
regarding how these grey area concepts manifest in other marginalised communities, such as those identifying as LGBTQ or those from ethnic minority groups.

Gender has previously been identified as one of the most important predictors of suicide in later life (Canetto, 1992), with older men being at significantly higher risk of using lethal methods of suicide (Neufeld and O'Rourke, 2009). Despite this, Canetto (1992) highlighted the absence of attention in research on older men. Supporting this, the majority of the included empirical studies (30 of 32 articles) included samples that were made up of majority female participants (range from 53 to 85% of participants studied). However, whilst gender plays a strong role in suicide rates in later life (Canetto, 1992), the relationship between gender and grey area behaviour expressions is less clear. For example, whilst Cukrowicz et al. (2011) found higher rates of suicide ideation in men, Lyu et al. (2020) reported a statistically comparable prevalence of suicide ideation between older men and women. However, they found that predictors of suicide ideation were shown to differ between genders. For women, fearlessness about death, family responsibility and social activities significantly predicted suicide ideation, whilst among men, only psychological inflexibility predicted suicidal ideation. Future research should look to further scrutinise the role of gender in the development and expression of grey area behaviours.

#### Development of a conceptual framework

This review aimed to identify and explore grey areas in suicide research that are unique to later life, and to translate this body of knowledge into a broad conceptual framework (*see* Figure 2). This conceptual framework highlights the four key 'grey area' concepts identified in the systematic scoping review, as well as the relationship between each: (a) completed life and existential loneliness (also including feeling 'tired of life'); (b) death wishes, thoughts and ideation; (c) death-hastening behaviours and advanced directives (*e.g.* voluntary stopping of eating or drinking); and (d) self-destructive or self-injurious behaviours (including self-neglectful behaviours).

It is noteworthy that whilst this conceptual framework highlights a number of key factors that protect against the development of these grey area expressions, the research included in this review did not seek to explicitly target or treat these grey area concepts (aside from Raue et al., 2010). Nonetheless, it is envisaged that such a framework might help identify opportunities for further engagement with older adults whose experiences may not align to more traditional suicidal presentations found in younger and middle-aged populations. We believe that this conceptual framework will provide a first step in helping policy makers, researchers, professionals, and people who work and live with older adults to progress towards identifying more tailored preventive measures and early interventions aimed at targeting suicide-related behaviours that are unique to, but common in, later life. Combined with other frameworks and models used in suicide prevention and interventions (e.g. O'Connor, 2021), our new conceptual model can help to bring a more nuanced understanding of precipitator factors, motivation and volition towards suicide when working with older people. Early detection of expression of these grey area behaviours is crucial, given that the results presented imply a sequential



#### Protective factors:

Social connectedness; satisfaction in one's social life; high level of purpose; perceived control over one's life; low levels perceived burdensomeness and/or hopelessness; low levels of functional disability

Figure 2. A conceptual model of the 'grey areas' of suicide-related expression in later life. *Notes*: This conceptual framework highlights the four key 'grey area' concepts identified in the systematic scoping review, as well as the relationship between each, and factors that protect against their development. The four identified concepts are: Concept 1: completed life and existential loneliness (also including feeling 'tired of life'); Concept 2: death wishes, thoughts and ideation; Concept 3: death-hastening behaviours and advanced directives (*e.g.* voluntary stopping of eating or drinking); and Concept 4: self-destructive or self-injurious behaviours (including self-neglectful behaviours). Based on the identified protective factors, developing an enhanced understanding of individuals' conditions or attributes (living environment, conditions, skills, strengths, resources, personal character, support networks or coping strategies) can help health-care providers enhance protective factors via interventions and to prevent the development of the identified grey area expressions.

relationship between the identified concepts. Indeed, early expressions of living a completed life may transition to a desire to die or attempts to hasten death (Hafford-Letchfield *et al.*, 2020), and appear to precede direct suicide attempts (*e.g.* Kjølseth *et al.*, 2010).

A lack of theoretical and methodological consistency in suicide in ageing research has been discussed previously (Van Orden and Conwell, 2011; Cavalcante and Minayo, 2015). The nature of the present review highlights the need to understand the unique (grey area) factors associated with older people's suicide risk, and to be able to differentiate these from a broader acceptance that their lives are coming to an end. Some of the grey areas surrounding existential notions of a completed life and wish to die might manifest independently of a diagnostic/psychological definition of depression. More importantly, the belief that life is not worth living represents dissatisfaction with quality of life as it is. Targeting these areas such as life dissatisfaction may be a fruitful avenue for individuals facing such circumstances. This also raises the question regarding the effectiveness of existing screening tools and assessment practices in identifying risk of suicide in later life which focus predominately on more explicit suicide-related behaviours or risk factors.

#### Wider influential factors

A recent systematic review of current measurement tools designed for older adults to assess suicide ideation (Gleeson *et al.*, 2021) found wide variations. The authors highlighted the lack of consideration across gender, culture and minority status, and

for the views of professionals and older people themselves to be considered. While age-appropriate measures appear to be needed, based on findings of different factors affecting wishes to live or to end one's life with age, there is a danger of perceiving 'older people' as a single homogenous group. Prevalence estimates of suicide in older age groups have reported differences across cultural and ethnic groups (Cukrowicz *et al.*, 2011; Canetto, 2017), suggesting a need for further nuance within measures of suicide ideation. For example, the notable gender difference in rates of suicide in older people needs further research. The broader social and environmental factors (such as financial security, access to health care and living conditions) that could have additional influence on wishes to die or to continue with life need to be considered in future research exploring these grey areas (Hodge, 2016; Gleeson *et al.*, 2021).

Across many studies in this review, the majority of older people were not clinically depressed. This underlines the importance of looking beyond psychiatric models and instead adopting a holistic approach to the issue of suicide in later life (De Leo, 2022). An improved understanding of individuals' conditions or attributes (living environment, conditions, skills, strengths, resources, personal character, support networks or coping strategies) can help health-care providers and mental health professionals to prevent the development of the identified grey area expressions, and enhance protective factors via interventions. Fostering social trust and hope, for example, after a significant bereavement, can reduce difficulties in the situations faced (Cheng *et al.*, 2020; Cui and Fiske, 2020; Heisel *et al.*, 2020) and prevent social withdrawal that could lead to a wish to die or suicide ideation.

The findings presented clearly characterise the 'in-between' phase of intending and performing self-directed death as living in a paradoxical position. When faced with people with mental capacity who sincerely believe that life is no longer worth living, mental health professionals feel highly challenged (Werth *et al.*, 2000; Stewart *et al.*, 2010). Rationality might contribute to the decision to terminate one's life, but the studies in this area indicate that people should not be approached merely as independent, autonomous and self-determining agents, but rather acknowledged as human beings struggling with life in all its ambiguity. This calls for sustained ethical engagement with older people, and their wishes and desires, by recognising that they are highly determined to die at a self-appointed moment, although these wishes appear to be fluid and might shift or change.

#### Implications for practice

This review indicates a number of factors that may protect individuals against the development of these grey areas, including: social connectedness (Ayalon and Shiovitz-Ezra, 2011; Stolz *et al.*, 2016; Cheung *et al.*, 2017) and satisfaction in one's social life (Stolz *et al.*, 2016; Bernier *et al.*, 2020), high level of purpose (Bonnewyn *et al.*, 2014) and perceived control over one's life (Bonnewyn *et al.*, 2014; Stolz *et al.*, 2016), low levels of perceived burdensomeness and hopelessness (Cukrowicz *et al.*, 2013; Guidry and Cukrowicz, 2016) and low levels of functional disability (Fässberg *et al.*, 2014). Developing interventions that enhance these factors in individuals at risk of developing these grey area expressions will have high levels of therapeutic impact.

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There is a need for those working directly to support or care for older people to have the right language, confidence and skill to discuss these issues and/or to take up the initiative to articulate one's own concerns when these conceptual areas are observed (Hafford-Letchfield *et al.*, 2020). Further, leaders of care services will need to be confident in supporting staff, other members of the multi-disciplinary team, family members and advocates when faced with challenging situations, such as the expression of a wish to die. For example, a wish to die may be expressed in several ways. There is a whole range of expressions: the desire not to prolong life, the wish to die 'quickly', the wish to hasten death, the wish to end life, a suicidal thought and others. The differences in expression and meaning can be subtle such that it may be difficult to distinguish between them, and lead to confusion for care staff and relatives (Guirimand *et al.*, 2014). This further highlights the importance of early assessment to identify accurately specifically how these grey areas are being assessed, as well as the reasons why.

#### Implications for policy and society

Seminal work by Rose (1981) highlights the importance of adopting a 'mass strategy' approach when designing public health interventions to reduce negative outcomes in 'high-risk' individuals. This suggests that interventions should not be focused only on those older adults deemed to be at a greater risk for developing these grey area expressions, but older adults in general. van Wijngaarden et al. (2018) argued that the primary focus in debates on self-directed death should be on how to build an inclusive society where people may feel less unneeded, useless and marginalised, and professionals and providers are important advocates. Care professionals also need to be able to recognise and engage with older people who may be experiencing existential loneliness. They also require an understanding of the effects of the various types of loss experience in later life and the interpersonal and structural impacts of ageism in society (WHO, 2021). It is therefore important to explore all possible areas of suffering with older adults including physical, psychological, existential and social, alongside expressions of personal autonomy (such as in VSED), and encourage ethical reflexivity in relation to the quality of life of people who prefer to die than to carry on living (Kashaniyan and Khodabakshi Koolaee, 2015).

#### Recommendations for future research

This scoping review explored how suicide-related grey areas are expressed in older adults. The findings of this review also highlighted some gaps in research such as:

- How to promote a more holistic approach to suicide research on later life which expands our understanding of social and environmental determinants of thoughts and actions related to suicide.
- What screening or assessment tools can encourage more in-depth conversations with older people and their advocates about thoughts and behaviours related to suicide?
- The need for greater use of community participatory research methods in which the voices of older people based on their own perspectives and experiences are central.

- The need to reflect greater diversity in research exploring these concepts, including people in older age groups, men at high risk and other people with protected characteristics, such as sex and gender diversity, ethnicity and culture.
- Development of early intervention strategies to target these grey areas at first expression, which may be addressed through group and psychotherapeutic interventions that focus on enhancing health, resources and values about later life.
- Recognise the impact of service culture and service quality on older people's experiences.

#### **Conclusions**

The scoping review and resultant conceptual framework highlight the need for these grey area concepts to be integrated into current understanding and prevention strategies for suicide in later life. This may involve unifying research from different disciplines, with policy themes on ageing such as healthy ageing, concepts of promoting person-centredness within service provision and giving greater emphasis to citizen participation. Further, being able to understand the individual experiences and pathways within suicide research can help to inform and enrich assessment and interventions, and to increase the potential to relate any theoretical concepts to their implementation. The body of research within this scoping review did not clearly delineate how preventive interventions should be designed to target these grey area expressions. The research, however, highlights the potential for wider social and therapeutic interventions (Kashaniyan and Khodabakshi Koolaee, 2015; Heisel et al., 2020; Lutzman and Sommerfeld, 2021). A combined intervention of support might involve medical and non-pharmacological interventions (Wand et al., in press), and include interpersonal therapies based on: identifying and clarifying factors contributing to the individual's psychological distress (Lapierre et al., 2015; Hafford-Letchfield et al., 2020), enhancing social connections, engaging in physical and social activities, and identifying negative interpersonal interactions (van Wijngaarden et al., 2019; Laflamme et al., 2022). Future research should confirm this proposal and directly assess the efficacy of targeting these grey areas using combined interventions.

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Conflict of interest. The authors declare no conflicts of interest.

**Ethical standards.** None required as this review paper is based on published research already in the public domain.

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