

# **Confronting one's own end of life**

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## Summary

The ageing population, particularly the increasing number of people aged 80 and over, imposes significant challenges on healthcare providers, policymakers and society to ensure high-quality individual care. Given the highly heterogeneous health and death trajectories, supportive psychosocial care that goes beyond addressing physical needs is necessary, considering psychological, emotional, social, and spiritual needs. Age or disease-related physical and mental losses can evoke the subjective perception of being closer to death and trigger existential questions on life and death. A process of adaptation to this debilitating situation that involves reconstructing meaning in life is decisive in experiencing existential health or existential suffering. Confronting one's own end of life may stimulate this process of adaptation and even stave off distress and foster personal growth. However, research on behavioural and mental confrontation with one's own end of life and related effects on measures of psychosocial comfort is limited. Evaluated approaches to confronting one's own end of life show beneficial effects but the mechanisms of actions remain largely unexplored. Additionally, individual strategies of those affected apart from existing (semi-)professional approaches have been inadequately addressed, particularly concerning people in old age. The experiences and preferences of individuals approaching the end of life can offer new insights for implementing new support concepts in end-of-life care.

In two dissertation projects, this dissertation aims to investigate how confronting one's own end of life affects well-being when approaching death due to age or life-limiting diseases. Based on the results, this dissertation discusses mechanisms of actions of confronting one's own end of life, and practical implications for developing low-threshold support concepts to increase well-being are derived.

In dissertation project 1, a systematic review of quantitative, qualitative and mixed-methods reports was conducted to synthesise the existing knowledge of the effects on older individuals and those with a life-limiting disease of different approaches to confronting one's own end of life. The results suggest a clear trend toward beneficial effects on psychosocial comfort. However, the scarcity of included qualitative studies exploring individual strategies to confront end-of-life issues highlights the need for a stronger focus on research from first-order perspectives, specifically the experiences and viewpoints of those directly affected. Therefore, for dissertation project 2, a qualitative research design employing a semi-structured interview guide was chosen. This project aims to explore how people aged 80 and over or with a life-limiting disease confront the end of their lives and how they experience the effects of doing so. Both participant groups reported that theoretical education, preparing for the end of their lives

(e.g., funerals), talking about death-related topics, reflecting on death-related topics, and coping with the approaching death in a spiritual sense had positive effects on their self-confidence, self-determination and relief. The need for confrontation and the desire for low-threshold and accessible support services to address their existential and spiritual issues were highlighted.

The results of the dissertation projects reveal discrepancies between existing psychosocial support in the care system and the preferences of people nearing death. Confronting one's own end of life, whether through (semi-)professional existing approaches or in private contexts, has beneficial effects but is underused due to barriers in accessibility and visibility. The dissertation discusses broader implications for the person-centred healthcare system, education, society and research, aiming to contribute to the development of supportive care of existential issues by confronting issues of life and death.

## **Zusammenfassung**

Die alternde Bevölkerung, insbesondere die steigende Anzahl von Menschen im Alter von 80 Jahren und älter, stellt unser Gesundheitssystem und deren Akteur\*innen sowie unsere Gesellschaft vor eine enorme Herausforderung. Der Versorgungsbedarf wird aufgrund von einer höheren Morbidität, Einschränkungen in den alltäglichen Aktivitäten und Multimorbiditäten, die mit dem Alter vermehrt einhergehen, steigen. Aufgrund stark heterogener Gesundheits- und Sterbeverläufe ist eine unterstützende psychosoziale Betreuung erforderlich, die über die medizinisch-pflegerischen Bedürfnisse hinausgeht und auch psychologische, emotionale, soziale und spirituelle Bedürfnisse berücksichtigt. Alters- oder krankheitsbedingte körperliche und geistige Einbußen können die subjektive Wahrnehmung hervorrufen, dem Tod näher zu sein, und somit existenzielle Fragen zu Leben und Tod auslösen. Entscheidend für das Erleben von existenzieller Gesundheit oder existenziellem Leiden ist ein Anpassungsprozess an diese belastende Situation, der die Rekonstruktion von Lebenssinn beinhaltet. Die Konfrontation mit dem eigenen Lebensende kann diesen Anpassungsprozess anregen und sogar existentiellen Stress mindern und das persönliche Wachstum fördern. Die Forschung zur Konfrontation mit dem eigenen Lebensende und die damit verbundenen Auswirkungen auf das psychosoziale Wohlbefinden ist jedoch begrenzt. Evaluierte Interventionen zur Konfrontation mit dem eigenen Lebensende zeigen zwar positive Effekte, die Wirkmechanismen sind jedoch noch weitgehend unerforscht. Darüber hinaus wurden individuelle Strategien der Betroffenen neben den bestehenden (semi-)professionellen Interventionen nur unzureichend untersucht, insbesondere in Bezug auf Menschen im hohen Alter. Die Erfahrungen und Präferenzen von Menschen, die sich dem Lebensende nähern, können neue Erkenntnisse für die Umsetzung neuer Unterstützungskonzepte bieten, die den Bedürfnissen gerecht werden.

In zwei Dissertationsprojekten soll untersucht werden, wie sich die Auseinandersetzung mit dem eigenen Lebensende auf das Wohlbefinden auswirkt, wenn man sich dem Tod aufgrund von Alter oder lebenslimitierenden Krankheiten subjektiv näher fühlt. Basierend auf den Ergebnissen werden in dieser Arbeit Wirkmechanismen der Auseinandersetzung mit dem eigenen Lebensende diskutiert und praktische Implikationen für die Entwicklung niedrigschwelliger Unterstützungskonzepte zur Steigerung des Wohlbefindens abgeleitet.



In Dissertationsprojekt 1 wurde ein Systematic Review basierend auf quantitativen, qualitativen und Mixed-Methods-Studien durchgeführt, um das vorhandene Wissen über die Auswirkungen verschiedener Ansätze der Auseinandersetzung mit dem eigenen Lebensende auf ältere Menschen und Menschen mit einer lebenslimitierenden Erkrankung zu evaluieren. Die Ergebnisse deuten auf einen klaren Trend zu positiven Auswirkungen auf das psychosoziale Wohlbefinden hin. Die geringe Anzahl der einbezogenen qualitativen Studien, die sich mit individuellen Strategien zur Auseinandersetzung mit dem Lebensende befassen, unterstreicht jedoch die Notwendigkeit einer stärkeren Fokussierung auf die Forschung aus der Betroffenenperspektive.

Daher wurde für das Dissertationsprojekt 2 ein qualitatives Forschungsdesign genutzt und Interviews mittels semi-strukturiertem Interviewleitfaden erhoben. In diesem Projekt wurde erforscht, wie sich Menschen ab 80 Jahren oder mit einer lebenslimitierenden Erkrankung mit dem eigenen Lebensende auseinandersetzen und wie sie die Auswirkungen der Auseinandersetzung erleben. Beide Teilnehmer\*innengruppen berichteten, dass die theoretische Aufklärung, die Vorbereitung auf das Lebensende (z.B. Planung der eigenen Beerdigung), das Sprechen über todesbezogene Themen und das Nachdenken über Themen zu Leben und Tod im spirituellen Sinne positive Auswirkungen auf Zuversicht, Selbstbestimmung und Wohlbefinden hatten. Die Notwendigkeit der Auseinandersetzung und der Wunsch nach niederschweligen, zugänglichen und flexiblen Angeboten, die spirituelle und existenzielle Bedürfnisse berücksichtigen, wurden durch die Zielgruppe hervorgehoben.

Die Ergebnisse der Dissertationsprojekte zeigen Diskrepanzen zwischen der bestehenden psychosozialen Unterstützung innerhalb des Versorgungssystems und den Wünschen der Menschen auf, die dem Tod nah sind. Die Auseinandersetzung mit dem eigenen Lebensende, sei es durch bestehende (semi-)professionelle Ansätze oder in privaten Kontexten, hat positive Auswirkungen, wird aber aufgrund von Barrieren in der Zugänglichkeit und Sichtbarkeit zu wenig genutzt. Die Dissertation erörtert weitergehende Implikationen für das Gesundheitssystem, Bildung, Gesellschaft und Forschung mit dem Ziel, einen Beitrag zur bedürfnisgerechten Versorgung durch die Auseinandersetzung mit todesbezogenen Themen leisten zu können.

## List of Abbreviations

EAPC European Association for Palliative Care

NIH National Institutes of Health

WHO World Health Organization

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## 1. Introduction

The ageing population and the rapid increase in the number of people aged 80 and over pose challenges for policymakers, healthcare services and public health (1, 2). By 2070, the proportion of people aged 80 and over is expected to reach 13% (3). Since statistically the increase in age is associated with a higher likelihood of health problems, many people will be confronted with frailty, multimorbidity, cognitive decline and chronic illnesses, especially when coming closer to death (4, 5). It is indispensable to assume that society is facing increased support needs (2). Even now the demanding healthcare environment does not regularly allow for individualised care that considers physical, psychological, emotional, social and spiritual needs (6). With the ongoing demographic shift, healthcare systems are facing growing challenges to ensure good healthcare (7). These unprecedented population changes will come with a higher demand for improved care at the end of life. The years lived without good health increase and therefore represent a global challenge for future end-of-life care (8). The prioritisation of end-of-life care, particularly in consideration of the intraindividual needs and thus the provision of adjusted support becomes particularly apparent (9). More knowledge is needed about the preferences and wishes regarding care at the end of life or in late life (10). Therefore, the perspective of those directly affected by the effects of multimorbidity and frailty requires greater attention (11).

Nearing the end of one's life and the threatening awareness of one's finitude can lead to discomfort or even existential distress (12, 13). Against this background, it is particularly important to meet people's individual needs to maintain psychological comfort when approaching death. Psychosocial and spiritual needs come to the fore alongside physical needs and are often related to or even used interchangeably with existential needs (14-18). The massive health-related changes challenge the ability to adapt to different situations and maintain a sense of coherence and orientation (14, 19, 20). The process of adaptation may even enable personal growth but may also cause existential despair if the approach to adaptation is dysfunctional (21, 22). Confrontation with issues of life and death and existential questions is also discussed as a decisive factor in whether the process of adaptation can succeed (21, 23-25). To date, however, research on confronting one's own end of life and related concerns and questions is limited, especially when it comes to people aged 80 and over (26, 27). Existing psychosocial interventions, ranging from educational approaches to intensive face-to-face counselling interventions that focus on confronting existential issues are often the subject of research than individual strategies (28).

This dissertation aims to address these gaps and describe the possible effects of engaging in different approaches of confrontation when nearing the end of life. It is crucial to know whether confronting existential issues when nearing the end of life may meet the individual needs of the people affected, whether mechanisms of action can be defined and whether the individual has preferences and wishes on how to confront these topics. The results of this dissertation can contribute to developing professional and informal support frameworks that provide a basis for confronting essential issues at the end of life.

Following this introduction, Chapters 2 through 5 summarise the theoretical background of this dissertation, including an overview of care and well-being at the end of life and a state of research on confronting the end of life. Chapter 6 presents the objectives and methods used in the dissertation projects. An outline of the peer-reviewed publications that provide the basis for the dissertation is given in Chapter 7, while the full publications are presented in the appendix. The findings of the publications include mechanisms of action for confronting the end of life. The opportunities to enable a confrontation with one's own end of life and relating to existential issues within the framework of spiritual care that is meant to address existential questions (29, 30) are discussed in Chapter 8. In Chapter 9, implications for research and practice are derived and assigned to the following levels: healthcare system, education and training, society and community and research. In Chapter 10, the methodological strength and limitations are discussed, and in Chapter 11, a summarising conclusion is drawn.

## 2. Nearing the end of life

### 2.1 The end of life

The end of life is a stage in our life span that every human will experience and may last days or month. As life expectancy increases, the end of life is emerging as a distinct phase of life, but consensus about the term in academic and clinical settings is lacking (31). Research in this field states that the end-of-life trajectory has changed in recent decades due to prolonged life expectancy and advances in medical care and, therefore, the end of life is challenging to define. The onset of this unique phase is controversially discussed (32). Most commonly, the definition of end of life includes two core aspects: a disease-centred perspective, i.e., a period of irreversible decline in health status due to injury or disease, and a time-based perspective, i.e., an outlined time frame of life expectancy, which is commonly not rigorously defined (32). The National Institutes of Health (NIH) confirm the lack of definitional clarity for several terms including end of life in their State-of-the-Science Conference on improving end-of-life care (33).

A common understanding of this period is crucial in care settings for clarifying individual issues concerning the progression of decline at the end of life and for health and social care planning on institutional, societal and even communal levels.

Two frequently used definitions should be mentioned: First, the definition of the NIH encompasses the presence of a progressive chronic disease with severe persisting symptoms or functional impairments that can lead to death (33). This definition is limited to people who have a life-limiting illness and does not include those who are nearing the end of life due to age-related health declines. End-of-life care usually refers to people with life-threatening illnesses but neglects the oldest old (2). Age-related losses or frailty are only mentioned as possibly causing a life-threatening illness or occurring as co-morbidities (33). Second, the European Association for Palliative Care (EAPC) describes a period of one or two years marked by an awareness of a life-limiting illness on the part of the patient or their relatives or caregivers (34).

An article by Nolan and Mock (35) refers to a definition contained in the United States Institute of Medicine Report by Gelband et al. (36), which considers fatal health conditions in a broader sense and is used here as a working definition, since age-related declines are also included: *“the period of time during which an individual copes with declining health from an ultimately terminal illness, from a serious though perhaps chronic illness, or from the frailties associated with advanced old age – even if death is not clearly imminent”* (36 p.22).

## **2.2 Finitude**

The term finitude or finite life is by definition often equated with mortality and belongs to human life, meaning that every life ends irrevocably with death (37). Facing the limitations of human life, finitude often describes an awareness of the imminence of one's death (38). Death can be seen as the ultimate proof of the finitude of human life (39). Heidegger (40) states that finitude encompasses the anticipation or authentic being-toward-death and therefore is linked to our self-understanding and world-understanding, which is also fragile, vulnerable and grounded in an final end.

Thoughts of one's finitude come more to the fore as the end of life approaches and trigger the awareness that the future and forthcoming changes are not controllable in this aspect (37).

## **2.3 Feeling close to death**

With advancing age, an age-related decline in functions of physical health and mental health shapes the individual's late-life trajectory (41, 42). Therefore, older adults are more likely to perceive their remaining lifetime as limited, due to experiencing and/or anticipating losses (43). This subjective nearness to death can also be caused by witnessing friends or relatives with age-related issues. As a consequence, this period is often marked by the awareness of one's own end of life (44).

The presence of one's impending death and the feeling of being closer to death may also occur when being diagnosed with a life-threatening or life-limiting disease such as cancer (45).

According to Terror Management Theory (TMT), the awareness of one's own end of life and that life is not infinite may cause unbearable psychological discomfort and leave people vulnerable to anxiety. Accompanying profound existential challenges can lead to psychological distress (44, 46) as part of a process of a psychological adjustment of self (14, 19).

### **3. Care at the end of life**

#### **3.1 End-of-life care**

End-of-life care describes the care and support that is given to people in their last years, months, weeks, days or even hours and is consequently used ambiguously (47). The period of receiving end-of-life care is usually longer than the phase during which someone is considered to be dying (48). The NIH provides no formal definition of end-of-life care since the term ‘end of life’ is not defined exactly (33). Nevertheless, commonly used content-related aspects that occur in research and practice are summarised in the following. The gold standard framework for optimum care delivery at the end of life in the United Kingdom, endorsed by the National Institute for Health and Clinical Excellence (NICE) (49) points out the aspect of living well until death. It outlines that care providers are meant to respect and meet the individual’s needs when nearing the end of life to provide the opportunity to die with dignity (50). These needs are further defined by the United States Department of Elder Affairs: physical, psychological, social, spiritual and practical needs of the patient and related caregivers should be considered and met. According to many definitions, the target group of end-of-life care are people with life-limiting illnesses. The UK Department of Health and Social Care provides a definition that considers the variable death trajectories by encapsulating a breadth of different healthcare scenarios such as frailty (51).

The different definitions unite the orientation to the individual needs of people who are nearing death. One only definition might not satisfy the multivariate and dynamic needs of highly individual people (52).

#### **3.2 Palliative care**

The terms ‘palliative care’, ‘terminal care’, ‘supportive care’ and ‘end-of-life care’ are often used synonymously and describe care when nearing the end of life (31). That can sometimes lead to confusion for healthcare providers, policy makers, patients and their next of kin. The World Health Organization first defined palliative care in 1990 and refined this definition in 2002 (53). “*Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual*” (54 p.84). The wide recognition of providing palliative care services in the early stages of the disease trajectory and the consideration of not only physical but also emotional and spiritual needs were stressed. In addition, the consideration has broadened in that the health and well-being of family members



and carers were established as a main aspect (54). This definition remained unchanged but the aim of integration of palliative care into a national person-centred healthcare system was endorsed (7). In 2009, the EAPC developed recommendations on cross-country standards and norms for the delivery of palliative care services in Europe (34). The aim was to generate a common terminology and values of good care, and in this context, the patient group was redefined to include not only cancer patients and to evaluate and elaborate on palliative care services and settings. However, these definitions, which shape the global understanding of palliative care, are over a decade old. Most recently, the recommendations for the standards and norms for palliative care were revised to develop new concepts in palliative and supportive care by the EAPC Board (55). The integration of neonatal, geriatric and dementia care within palliative care received strong consensus and improved information transfer, access to palliative care and the need to improve digital health technologies, to name the main results. Focusing on the service users, the shift from cancer patients to all patients regardless of diagnosis poses the question of whether a comparable care system exists for people in old age with cumulative mental and physical losses. Several researchers stated that research on access to palliative care for old people is scarce and more studies are required on their needs and preferences when nearing death (10, 56, 57).

Elaborating on the differentiation between palliative care and end-of-life care, terms that are used interchangeably, the NICE definition is used for this dissertation: “*End of life care enables supportive and palliative care needs to be identified and met throughout the last phase of life and into bereavement.*” (49 p.3). Again, though, the time frame of the last phase of life is not determinable and needs may arise before any arbitrary cut-off date (52).

### 3.3 Whole-person care

People in old age and people with life-limiting or life-threatening diseases may have complex care needs, indicating nonlinear health and disease trajectories. Ageing is described as a process of deterioration and loss and often comes along with decreased well-being (58). Consequently, the care process should be based on the person’s needs, preferences and values and not only on the requirements of the healthcare system (4).

The discourse of patient-centeredness or person-centeredness as an approach to care has its origins in humanistic psychotherapy and is based on the work of Carl Rogers (59), who brought profound respect for the individual human being into focus. The encounter with a person should therefore be characterised by empathy, acceptance and especially communication to enable a holistic view of the person. Shared decision-making and sensitivity to the special needs of people are central components to creating a ‘*growth-promoting climate*’ in which the resource-

orientated perspective is lived. These guiding principles should be the basis for any encounter between professionals and clients (59).

The term ‘person-centred care’ is often used interchangeably (60, 61) with ‘whole-person care’ and includes the following domains: respect and value, choice, dignity, self-determination and purposeful living or encouragement of continued social roles (62). The paradigm shift from physical and medical care to whole-person care influenced the care system theoretically and practically: Non-medical aspects of deteriorating life trajectories were highlighted and the inclusion of patients’ aims, needs and expectations became an important condition to improve each individual’s quality of life in care (4, 14).

For this dissertation, the term ‘whole-person care’ is used since the meaning of the whole person underlines the perception of the individual as a whole in the context of the social, emotional and spiritual environment (63). The term shifts away from the medical condition and brings a holistic understanding of the individual trajectories to the fore. The principles of whole-person care rather than the view of health as an absence of disease are proclaimed as an important aspect of quality of life and encompass compassionate care (14, 64).

In the context of palliative care, aspects of whole-person care are considered and highlighted in the WHO definition of palliative care: “...*whether physical, psychological, social or spiritual. The quality of life of caregivers improves as well*” (7), and the critical role of spirituality and existential psychosocial issues when nearing the end of life is recognised. Regarding the care system of people in their fourth age (people aged 80 and over), the whole-person approach appears less prominent (65).

Overall, the common healthcare practice evolved from illness-orientated care to care that promotes well-being on a physical, mental, emotional, social and spiritual level (63, 66). Healthcare services must be organised around people’s needs and expectations (67), resulting in better health outcomes, improved patient satisfaction and provider satisfaction (63, 68).

### **3.4 Care at the end of life in Germany**

In Germany, palliative care structures, often equated with end-of-life care (31), are organised in the inpatient and outpatient sectors. Outpatient palliative care includes both generalist palliative care, i.e., care provided to those affected by life-threatening diseases by non-specialised general healthcare professionals, and specialised palliative care, i.e., care provided to those affected by life-threatening diseases provided by an interdisciplinary team that is trained in palliative care at an advanced level (69). With the German Act to Strengthen Competition in Statutory Health Insurance in 2007, specialised palliative outpatient care has

been fully covered by the statutory health insurance (70). In a consensus committee comprising experts in the field of end-of-life care, the Charta, i.e., guiding principles and recommendations for action to enhance patient care at the end of life (71). Progress was taken even further with new legislation in 2015 to improve hospice and palliative care that focused on care at the end of life as a component of regular healthcare, including a legal basis for the financing (72). Currently, the possibilities of palliative and end-of-life care are strongly dependent on the region, as urban areas are better positioned than rural areas (73, 74).

In the view of existential psychosocial issues, the needs of people nearing the end of life often remain unmet (75-77). The field of psychosocial support is still not striking in Germany and needs to be anchored more firmly in end-of-life care (78). For example, the psychiatric symptom of demoralisation, which is associated with the end of life and includes hopelessness, helplessness and loss of purpose and meaning, is quite common and well described but has not yet been included in the international classification system ICD-10 (79). In the new version, ICD-11(80), demoralisation and related meaninglessness are included and thus will soon probably be billable to health insurers (79, 80). In the S3 Guideline 'Palliative Care for Patients with Incurable Cancer', psychosocial care is recommended (81), but it is given too little consideration in healthcare and research, especially in old age (82). To date, no system covers the costs of psychosocial support services by health insurance although consensus on the need for professional psychosocial support and coordination of support services is international (83, 84). In everyday life, volunteers commonly provide psychosocial and spiritual support, but the possibility of seeking professional support is rare (76).

## 4. Well-being at the end of life

### 4.1 Well-being in old age and at the end of life

Well-being is defined in direct relation to mental health and is described by the WHO as follows: “*Mental health is a state of well-being in which every individual realizes his or her own potential, can cope with the normal stresses of life, can work productively and fruitfully, and is able to make a contribution to her or his community*” (85). When talking about the construct of well-being, the oldest old often remain underrepresented, although well-being is likely to deteriorate in the last three to five years of one’s life (86). This may result in health inequity (2). Gerontological research is drawing attention to existential dimensions such as spirituality and meaning in life as important determinants of psychological well-being in late life. This is an extension of the previous view, which focused on the physical dimension and external factors such as social resources (2, 20).

The concept of positive ageing refers to a productive and active encounter with the changes and challenges of life in old age and at the end of life to enhance people’s well-being and participation. It is explicitly not an optimal state to be achieved, but an intraindividual process (86, 87). This concept is opposed to the definition of successful ageing, which emphasises three dimensions: 1) low probability of disease and disability, 2) high cognitive and physical functioning and 3) active engagement with life. This model is repeatedly criticised because it provides an unrealistic picture of ageing that ignores the spiritual dimension and unequal socio-economic conditions. Wong (88) adds a fourth dimension, namely meaning in life, as the result of successful restructuring and adaptation required due to age-related degradation processes. Büssing (20) propose spirituality as a further independent dimension of successful ageing.

Nonetheless, most research is not based on those who are affected (11). People in old age focus on maintaining the balance between losses such as physical deterioration and development such as transcendence and therefore an adjustment to the actual situation to maintain well-being (89). This flexible approach is in line with Erikson’s theory of psychological challenges in life that cause a tension between despair and ego-integrity that needs to be resolved to reach a state of reconciliation (90).

Summing up, the question remains of what needs people who are approaching the end of life have to enhance their well-being remains.

## 4.2 Needs in old age and at the end of life

The best-known model of needs was proposed in 1943 by the psychologist Abraham Maslow (91). According to this model, humans have basic needs on different levels: physiological, safety, belongingness/love as primary needs and self-esteem and the need for self-actualisation as secondary needs. The need for self-actualisation is also called a growth need, the highest level of needs that enables a realization of one's full potential and comes with having a good life and experiencing well-being (91, 92). If a need is satisfied, health and well-being are promoted, if unsatisfied, it contributes to ill-being (93).

People in old age and people nearing the end of their lives often experience individual complex health trajectories due to physical, psychological, emotional, and practical issues. Multiple health problems such as multimorbidity, frailty or life-limiting diseases may result in non-physical needs such as seeking meaning in life in addition to physical needs such as pain relief (94). Psychosocial and spiritual needs come to the fore and are often related to or used interchangeably with existential needs (14-18).

Previous research on healthcare needs and preferences of older people is scarce since studies mainly include people aged 60 or older and therefore may not be representative of the oldest old (95, 96). For people who are diagnosed as having a life-limiting illness, needs are better understood and comprise physical needs such as pain or fatigue, psychosocial and spiritual needs such as mental well-being, information needs such as being informed by carers, and healthcare service needs such as being regarded and respected as a unique human being (97).

Consequently, good end-of-life care should account for unique needs and preferences in different trajectories. Heyland et al. (98) developed a list of 28 components of care and ranked these according to their importance in healthcare settings. They identified five different dimensions of good end-of-life care, namely: medical and nursing care, communication and decision-making, social relationships and support, meaningful existence and advance care planning. The most important aspects for people at the end of life were trusting the doctor, avoidance of unwanted medical treatment of life support, the appropriate communication of information, continuity of care and life completion (98). The above-described needs are in line with the results of the review of Zaman et al. (99), who identified common conditions to experience a good death. They report on 11 conditions associated with a good death. Three of these 11 conditions require medical expertise; the other conditions are psychological, relational, spiritual, communicational or practical in origin and therefore do not necessarily require medically trained personnel (99).

The Economist Intelligence Unit published a Quality of Death Index that comprises indicators that imply better end-of-life experiences. These 13 indicators on preferences and needs of people at the end of life are consistent with those of Zaman et al. (99) and with results of the abovementioned qualitative study by Heyland et al. (98) and focus on comparable metrics: palliative care and healthcare environment, healthcare professionals and communication, affordability of care, quality of care including psychosocial support and community engagement (53, 100).

In conclusion, non-medical and non-physical needs are relevant alongside medical needs when nearing the end of life. This raises the question of what kind of non-medical and non-physical needs people experience and whether they are met in our healthcare system.

### **4.3 Non-physical needs when nearing the end of life**

From the challenges arising from death awareness and the approaching end of life, several supportive needs are probably even more prevalent alongside physical needs and medical care and therefore should be a central focus of care (15, 45). Indeed, diverse needs arise that cannot be assigned to one of the following dimensions but are intertwined (20) and belong to psychosocial, spiritual and existential dimensions.

These non-physical needs can be assigned to two levels: the healthcare level and the psychosocial level. Referring to a meta-synthesis of preferences and needs within ambulatory healthcare in old age that elaborates on needs on the healthcare level, it is important to feel like a meaningful human being and to maintain control and independence, for example, through shared decision-making (101). Further studies also report on the importance of creating and finding meaning and the feeling of being valued in healthcare settings and society (17, 95). The supportive and reciprocal relationship between patient and healthcare giver, encompassing kindness, friendliness and compassion, was an emotional aspect that was rated as a key preference (102, 103). The wish to talk about end-of-life topics and preferences for the last phase of life with healthcare professionals is frequently mentioned (76, 104, 105). Accordingly, relational, communicational and socio-emotional skills can be considered essential alongside medical needs and recorded as fundamental elements in care situations for people nearing the end of their lives due to old age or severe illness (103).

On the psychosocial level, people value connectedness to others and to self, a higher being or nature. To feel meaningful is a frequently mentioned need and is discussed as a determinant for completion (106). Through life review, time with next kin and friends, resolving conflicts and the possibility of saying good-bye, the feeling of meaning can be reached (106). On the one

hand these themes can serve as an affirmation of the whole person; on the other hand they contribute to others. Arnold et al. (16) report on seven core domains of end-of-life needs of hospice patients. Four out of seven are on a psychosocial level: social relationships, confronting death and dying, spiritual needs and personal change and adaptation to the new situation. These findings are supported by Lin et al. (107) in terms of coping with the new situation of feeling closer to death, relationships, a sense of faith and living meaningfully as conditions that determine psychosocial well-being. Henoch et al. (108) argue that these diverse needs to a large extent aim to maintain self-identity.

#### **4.4 Spiritual needs when nearing the end of life**

The concepts of existential and spiritual needs are frequently used interchangeably (14, 108, 109) and are related to each other. Hvidt et al. (110) propose the concept of the existential as an overarching theme for secular, spiritual and religious domains. Spiritual needs are characterised “*by normal expressions of a person’s inner being that motivates the search for meaning in all experiences and a dynamic relationship with others, self and whatever the person values*” (111 p.35). Those needs may be attained by following them to finish business, including life review, enabling and promoting involvement and control, a positive outlook, hope, meaning and purpose (22, 112). Focusing on the term ‘spiritual needs’ within this dissertation and encompassing psychosocial and existential needs, the effects on quality of life and well-being are undisputed (23, 75, 93, 113-115). The terms ‘spiritual needs’ and ‘existential needs’ will be equally used to cover as many non-physical needs as possible, which some people define as spiritual and others as existential. Committing to one term does not seem relevant in the context of this dissertation.

The importance of identifying potential spiritual needs is additionally stressed concerning those research projects that obtained experiences and wishes from a first-order-perspective. Qualitative studies are lacking in the context of healthcare and even in palliative care, though spirituality is a central component in the discipline’s orientation and history (109). To give an insight into patients’ perspectives, recent research revealed that 85% of patients with a life-limiting disease reported spirituality as being crucial in their healthcare and recovery and 67% desired to have spiritual needs met or be supported by their medical team (75). The results of another study showed that for nearly 40% of a total of 262 palliative care patients spirituality was very important (116). In a research project in Australia, Michael et al. (77) asked 261 patients whether they recognised spiritual/existential concerns and if they could name these. Around 62% identified at least one concern, such as fear of the dying process, loss of control, regret or loss of meaning. Balboni et al. (117) examined whether cancer patients see their

spiritual needs met and ascertained that around two-thirds of patients reported that their needs were met minimally or not met within healthcare. In healthcare, many people want their spiritual needs to be mentioned (118). For people in old age, data are scarce (119). The review by Hodge et al. (112) summarised qualitative research to scrutinise spiritual needs in old age but also included patients with severe and life-limiting diseases. They outlined spiritual needs containing spiritual practices, relationships with God, hope, meaning and purpose, interpersonal connection and professional staff interaction(112). Clements and Koenig (120) identified 14 spiritual needs of older persons but focused on religious perspectives without integrating the different facets of spirituality and the dynamic field in a secular world (121-123).

Summing up recent research, spiritual needs are complex and pool diverse dimensions, including social, and psychological needs (124). It is not crucial to make an assignment to one dimension or the other, but focusing on the individual and adequate treatment is decisive in relieving concerns and distress. People in old age and people with serious diseases want their spiritual needs to be addressed (30, 82, 112). Consequently, the interactions and initiatives to address these needs should be characterised by warmth, kindness and patience (112).

#### **4.5 Distress when nearing the end of life**

The awareness of one's death is triggered by physical and/or mental deterioration processes and often triggers reflection processes and concerns about life and death. The Terror Management Theory assumes that the need to survive and the consciousness of the inevitability of death causes an existential dilemma (13). Threatened by an acute awareness of death and the dilemma, people can experience high levels of discomfort and existential anxiety. This debilitating situation requires a reorientation to maintain meaning in life (125). In this process, existential questions arise that refer to fundamental issues of life and death (126, 127). Questions address the following themes: the value of life, connectedness, hope and one's place in this world (108, 128). If questions remain unanswered and meaning stagnates, people may get caught up in conflicts comprising a lack of coherence and orientation (126, 129, 130). Existential distress arises from a process of losing the self-image that causes suffering. In the literature, the meaning of '*existential suffering*' is interpreted according to the authors and overlaps with the terms 'existential pain', 'existential distress' and 'spiritual distress' (131). Cicely Saunders, the founder of the modern hospice movement, stresses in her total pain concepts the importance of existential needs besides physical needs and considers existential suffering as a result of meaninglessness (132). A review by Boston et al. (14) examined the concept of existential suffering and concluded that a lack of meaning or purpose, loss of connectedness to others, concerns about the dying process and the state of being, losing a sense of self, losses of hope,



autonomy and temporality are signals of existential suffering. According to Cassell (133), suffering is a state of losing the essential elements that determine one's role in life, and self-esteem may be extremely endangered.

It is undisputed that existential suffering must be addressed as part of holistic care as this form of suffering is often the most severe (14, 134). Cassel and Rich (135) stress the assertion of the multidimensional aspects of suffering and add that dimensions of suffering such as physical, psychosocial or spiritual do not afflict the person in isolation. Therefore, it is necessary to consider the total experiences and needs of a person nearing death (135).

Acceptance in the context of end-of-life care is commonly understood as the degree of acceptance of the assumption of the unavoidable end of one's own life and the unlived life in a life review (136). Current research findings show that an accepting attitude towards the own end of life may lead to higher grades of satisfaction (26, 137, 138) and is therefore relevant to increase well-being. Acceptance in turn correlates with the confrontation of impending death. Muszyński et al. (139) concluded that self-reflection, seeing death as a part of the worldview and seeing death as a natural part of life are components of an accepting attitude and people show only low or moderate levels of death anxiety, whereas negative emotions related to death and dying and an avoiding attitude are aspects of suppression of death-related thoughts and lead to high levels of death anxiety. Tang et al. (140) sum up that once death awareness becomes real, confronting one's own end of life without acceptance and proper support may even harm a terminally ill patient's well-being. According to the Three-Component Model of Death Acceptance by Wong et al. (141), which refers to the findings from the gerontological research field of successful ageing from an empirical point of view (142, 143), three qualities for the acceptance of death can be distinguished: 1) approach acceptance implies a religious or spiritual belief in a desirable afterlife, 2) escape acceptance is avoidance orientated and assumes that death provides relief from pain and suffering and 3) neutral acceptance recognises death rationally as an integral part of life, as a biological fact (141).

The attitude towards ageing processes and the attitudes towards one's own end of life require confrontation (37, 128) in that confronting death-related topics have positive effects on attitudes to death and can decrease death anxiety (144).

However, research remains scarce on attitudes to death and one's own end of life, especially for the group of people aged 80 and over but with greater urgency due to the proximity to death (26, 41).

## **5. Confronting the end of one's own life**

### **5.1 Defining confronting**

Confronting the end of one's own life is not an existing concept. It may, however, be understood as actively facing an existential challenge, in this context caused by the intimidating perception of one's own end of life and the finitude of life (37). Thus, confronting may stimulate a process of adaptation and reinterpretation of the current life situation (24, 145). Behavioural and cognitive efforts within the coping process are necessary to deal with destabilising situations that seem to exceed one's resources (146). According to Erikson (147), confronting the last great challenge in life through individual preparation and an intellectual and spiritual approach is the breeding ground for the development of wisdom and an accepting attitude towards one's death. An active form of coping is also supported by other scientists and discussed as an enabler for an accepting attitude to one's life and death (148, 149). If the coping process is effective, the person can come to terms with the individual realities and adjust to the new situation or perception of the approaching end of life (150). However, if coping is ineffective, isolation, the desire to die and subjection are possible consequences or evolving emotions (149, 150).

### **5.2 Chances and effects of confronting one's own end of life**

In the face of the challenging situation of approaching death, it is crucial whether the person can achieve a state of existential health through successful coping or whether existential suffering results (21, 26, 151). The people affected can often engage in a process of reconstructing meaning in life to operate within a new reality (150). Personal growth may emerge through successfully reinterpreting the current life situation (21). One may further differentiate between existing interventions of confronting finitude and individual strategies to face the end of one's life. Current research mainly evaluates existing interventions that mostly work on a psychosocial level, such as Dignity Therapy (114) or life review interventions (152). Beneficial effects on psychosocial comfort can be found for people with a life-limiting illness and for people in old age (153-155) and support the mentioned assumption that confronting the end of life can be profitable. In addition, educational offers and meaning-in-life interventions that address end-of-life topics and related issues have been evaluated as useful (156-158).

The question arises of how and if people engage in end-of-life confrontations and what forms of engagement are considered beneficial. A comparative overview is not yet known. Teo et al. (28) systematically examined various types of intervention approaches in psychosocial care at the end of life. The results suggest a pattern of positive outcomes in the sense of meaning and

quality of life. Confronting one's own end-of-life as a possible determinant of well-being and quality of life should be considered (159).

### **5.3 Approaches to confronting one's own end of life**

When coping strategies no longer provide relief in an end-of-life crisis, (semi-) professional interventions can be beneficial. According to Blanckenburg et al.(160), who systematically summarised psychological interventions in palliative care, approaches are to be aligned with the needs and concerns of the people. These can manifest themselves on different levels: social, physical, spiritual or psychological. Depending on the weighting of the symptoms, different forms of intervention are to be applied. Approaches that address these concerns and thus include confronting end-of-life topics include cognitive-based therapy, meaning-based interventions, dignity-based interventions, life review interventions, facilitating social support and facilitating end-of-life planning and communication. Another review conducted by Teo et al. (28) on psychosocial interventions for advanced cancer grouped existing interventions similarly: cognitive-based interventions, meaning-enhancing interventions, dignity therapy/life review/narrative interventions, other counselling interventions, education-only interventions and music, writing and other interventions.

The above-named approaches include existential topics on issues of living, dying and death. While some of the interventions focus more on appreciating one's life, other interventions are more orientated towards focusing on death-related issues and impending death. In conclusion, all approaches involve a form of confrontation when approaching the end of life and thus aim to reduce existential concerns and distress. Both reviews provide good overviews of the form of intervention but do not systematically summarise the impact on outcome measures of well-being. Outcome-orientated research projects are mostly related to a specific intervention. Primary studies on dignity therapy for people with life-limiting illnesses (161-163), meaning-enhancing interventions and life review interventions are quantitatively evaluated with positive outcomes in terms of psychosocial comfort (155, 156, 164). However, research on individual coping strategies in confronting the demanding challenges of the end of life is lacking. First-order perspectives are underrepresented (165), especially when regarding people in old age, and evidence on confronting the end of life in old age is scarce (27, 105).

The following unanswered questions arise from the analysis of the current state of research on the confrontation with one's own end of life:

- 1) What approaches to confrontation exist for people nearing the end of life?
- 2) What is the impact of confrontation on psychosocial comfort?

- 3) Do the ways people with life-limiting illnesses and people aged 80 and over confront the end of life differ?
- 4) How do people nearing the end of life confront death-related issues?
- 5) What are the wishes of those affected as to how to confront the end of their lives?

## 6. Objectives and methods

To address the abovementioned research desiderata, the overall research question for the dissertation is as follows: How does the confrontation with one's own end of life affect well-being when approaching death due to age or life-limiting diseases?

The dissertation is based on two projects dealing with the confrontation with one's own end of life by people approaching death, either due to old age or a life-limiting disease. Impacts on well-being, experiences and wishes for confronting death-related topics were addressed. After systematically summarising research on the effects of confronting one's own end of life, a qualitative design was chosen to meet the exploratory nature of the research question. An overview of the methodological approaches is presented in Table 1.

	Objective	Data collection	Data analysis
Dissertation project 1 (166)	To synthesise the existing knowledge on the effects of different approaches of confronting one's own end of life on older individuals and those with a life-limiting disease	Systematic review of quantitative, qualitative, and mixed-methods full research reports, additional electronic and hand searches, forward and backward citation tracking, and appraisal for methodological quality	Narrative synthesis using the meta-summary technique by Sandelowski and Barroso (171)
Dissertation project 2 (167)	To explore how people aged 80 and over or with a life-limiting disease confront the end of their lives and how they experience the effects of doing so	Qualitative interviews using a semi-structured interview guide	Inductive method: thematic analysis by Braun and Clarke (172)

*Table 1: Overview of the methodological approaches*

### Dissertation project 1:

A systematic review of full research reports was conducted to answer the following research question: *What is known about the effects of confronting one's own end of life on aspects of psychosocial comfort in older individuals and people with a life-limiting disease?* Electronic bibliographic databases were systematically searched for qualitative, quantitative and mixed-methods studies that met the selection criteria. The search was completed by a forward and backward citation search and a keyword search in Google Scholar. The retrieved abstracts and full texts of results were independently screened against the eligibility criteria by two

researchers. The quality of included studies was assessed using the Critical Appraisal Skills Programme (CASP) (168) for qualitative and quantitative study reports. Mixed-methods studies were appraised using the Mixed-Methods Appraisal Tool (MMAT) (169). The synthesis comprised extracting, grouping and formatting the results. Statements were grouped by outcome category to create major topics using MAXQDA Analytics Pro 2020 (170). Aggregation and synthesis of findings were conducted according to Sandelowski and Barroso (171). Meta-summary results can be used as an empirical foundation for developing qualitative research projects as the results of the summary can be seen as indexes of the experiences of the participants in the included studies (171).

#### Dissertation project 2:

Drawing on the results and the outlined research gaps of the systematic review a qualitative interview study was conducted to answer the following research questions: *1) How do people aged 80 and over people with a life-limiting disease confront the end of their own lives? 2) How do they experience the effects of confronting? 3) Do they have wishes regarding the confrontation of their own lives?*

Semi-structured individual interviews were conducted. The interview guide was based on the results of dissertation project 1. Participants were selected purposefully, and the interviews were audio-recorded and transcribed verbatim. Two researchers analysed a sample of transcripts according to the thematic analysis by Braun and Clarke (172), an inductive method that aims to find patterns in the meaning of data to create content-driven themes. The codebook was developed in an iterative process of interviewing and analysing a core set of transcripts independently by two researchers to minimise subjectivity. Data coding was performed using MAXQDA Analytics Pro 2020 (170), and data saturation, defined as the point at which no new themes emerged, was reached after ten interviews.

## 7. Publications

In the following, the abstracts of publications resulting from the dissertation projects are listed. The original publications are available in the appendix.

### Dissertation project 1:

#### **The effects of confronting one's own end of life on older individuals and those with a life-threatening disease: A systematic literature review**

Helena Kukla, Angélique Herrler, Julia Strupp, Raymond Voltz. *Palliative Medicine* 35 (10), 1793–1814 (2021). DOI: 10.1177/02692163211042528.

Two-year journal impact factor at the time of publication: 5,713

#### Abstract

**Background:** Awareness of the impending end of one's life can pose profound existential challenges, thereby impairing well-being. Confronting one's own end of life may be an approach to meet the psychological needs and consequently enhance overall well-being. Different approaches of confrontation have been evaluated positively using measures of psychosocial comfort. To date, there exists no systematic overview on the different ways of confrontation (e.g. psychosocial or individual coping approaches).

**Aim:** To synthesize the existing knowledge on the effects of different approaches of confronting one's own end of life on older individuals and those with a life-threatening disease.

**Methods:** A systematic review of quantitative, qualitative, and mixed-methods full research reports was conducted. The retrieved studies were screened and appraised for methodological quality by two independent reviewers based on MMAT and CASP. The findings were synthesized narratively using the meta-summary technique by Sandelowski and Barroso.

**Data sources:** Medline, PsycINFO, and Web of Science were searched from inception to 12/2020.

**Results:** N = 49 studies reported on different approaches of confronting one's own end of life, including psychosocial interventions, meaning-enhancing approaches, educational programs, and learning from lived experiences. The results suggest a clear trend toward beneficial effects on psychosocial comfort (e.g. anxiety, sense of meaning, well-being).

**Conclusion:** Low-threshold opportunities of confrontation have the potential to improve well-being and should be emphasized in practical implementation. The results can serve as a comprehensive basis for future research aiming to investigate the determinants of psychosocial comfort for people nearing the end of life.

**Dissertation project 2:****"My life became more meaningful": confronting one's own end of life and its effects on well-being-a qualitative study**

Helena Kukla, Angélique Herrler, Julia Strupp, Raymond Voltz. BMC Palliative Care 21(1), 58. DOI: 10.1186/s12904-022-00950-3.

Two-year journal impact factor at the time of publication: 3,113

Abstract

**Background:** The perception of being closer to death can be experienced due to old age or life-limiting diseases, and can pose profound existential challenges. Actively confronting death-related issues and existential questions may increase psychosocial comfort and stimulate personal growth, whereas dysfunctional coping may lead to existential distress. To date, research on individual and (semi-)professional approaches to confronting the own end of life and the effects on one's well-being remain scarce. Therefore, the aim of this study was to explore individual strategies and wishes in order to derive ideas for appropriate support concepts.

**Methods:** 21 semi-structured interviews were conducted with people over the age of 80 (n = 11) and with a life-limiting disease (n = 10). The interviews were transcribed verbatim and independently coded by two researchers according to Braun and Clarke's thematic analysis approach.

**Results:** While the use of (semi-)professional approaches (e.g., therapeutic support) to confronting existential questions in the shape of one's impending death was rare, individual coping strategies did have a positive impact on psychosocial comfort. There were hardly any significant differences between the participants aged 80 and over and those with a life-limiting disease in terms of individual coping strategies or how they approached the ends of their lives. Both groups reported that theoretical education, preparing for the ends of their lives (e.g., funerals), talking about death-related topics, reflecting on death-related topics, and contemplating death in a spiritual sense had positive effects on their assurance, self-determination and relief. The necessity of confrontation and a desire for low-threshold, accessible and flexible services to meet their existential and spiritual needs were highlighted.

**Conclusions:** There is both a desire and a need for the addressing of existential questions. Outside of private contexts, however, the participants possessed little awareness of support services that focused on confronting end-of-life issues, and rarely used such services. Efforts to raise awareness for psychosocial and spiritual needs should be implemented within the care system, together with low-threshold support concepts, in order to increase psychosocial well-



being. More research evaluating individual approaches to confronting the own end of life is needed to better understand this determinant of well-being and its mechanisms of action. Trial registration: [www.germanctr.de](http://www.germanctr.de), DRKS-ID: DRKS00020577

## **8. Discussion**

### **8.1 The effects of confronting and potential mechanisms of action**

Drawing from the results of the review, four different approaches to confronting one's own end of life can be deduced: (1) psychosocial interventions, using a narrative therapeutic approach focusing on reflection on the life one has lived, (2) meaning-enhancing interventions, using counselling-based intervention focusing on strengthening the patient's sense of meaning, purpose, and dignity, (3) educational courses, focusing on the transmission of knowledge, and (4) experiential learning and practices, defined as personal experiences and actions regarding end-of-life topics (such as planning the funeral or talking about end-of-life topics) (166). Although mainly existing psychosocial or psychological interventions were researched, the approaches show a clear trend of beneficial effects of psychosocial comfort in terms of increasing well-being and quality of life and decreasing anxiety and depression. Hence, they represent a valuable form of psychosocial support when nearing the end of life. The scarcity of included qualitative research reports underlines the need to learn from those who are affected (11, 165, 173). Therefore, the second paper of this dissertation focuses on individual and heterogenous coping strategies.

As mentioned before, contemplating death-related topics and the immediacy of one's death is discussed as a source for personal growth (21, 23), but the underlying mechanisms of action are not yet fully understood. Due to the heterogeneity of people and cultures, it is also not possible to determine an optimal strategy for confronting the end of life to improve psychological comfort. People use different strategies: active coping strategies if resources are sufficient and defending if resources are limited and the feeling of being overwhelmed arises (24). Fundamentally, however, the researchers agree that coping can be successful when psychologically adjusting to a destabilising situation or maladaptive when preventing an adaptation process through defending the realities of life (21, 24). The different approaches to confronting may contribute to the process of adaptation and have their rationale in contributing to psychosocial comfort. The identification of the mechanisms of action combined with the preferences and wishes of those affected could provide new insights for implementing new support concepts in caring at the end of life.

Meaning in life, defined as the will to be meaningful (128), is discussed as resource and buffer against distress at the end of life (173). Frankl indicated that meaning was the main driving force in life that enables one to achieve a sense of peace (174). Meaning enables one to create or recreate a comprehensible and manageable reality when crises emerge and to better cope with their realities while experiencing a new meaning of existence (150). This philosophical

point of view is comparably presented by Wong (128): “*A meaningful life is understandable or coherent*” (p.12). Going back to Antonovsky (175), the ‘*sense of coherence*’ represents a life orientation, since a strong sense of coherence may help to mobilise resources to cope with concerns and distress and consequently determines a person’s position on a health-disease continuum (176). The sense of coherence model as a core concept of salutogenesis has three main components 1) comprehensibility, 2) manageability, and 3) meaningfulness. The third component seems to meet the concept of meaning by pointing out that life perception and challenges in life are perceived as worthy to engage in or otherwise as a burden we like to avoid (177). Rosenfeld et al. (178) consider meaning as a powerful mediator of quality of life and therefore as a key component that should be addressed in psychosocially orientated end-of-life interventions. The importance of meaning and its consideration as a potential mechanism of action is supported by applied research: people who felt a sense of meaning in life were able to experience a sense of well-being during severe illness, whereas people without a sense of meaning experienced suffering (14).

In research by Chochinov et al. (114, 161), the founders of the Dignity Therapy, dignity is a central component of interventions. Focusing on a sense of esteem and inalienable worth, dignity can relieve distress. People have the opportunity to reflect on meaningful issues and life events that matter most or that they want to be remembered by recounting parts of their lives and attitudes (161). Again, meaning-making was found to be a central component of life-review-based Dignity Therapy (144). Some authors assign dignity to autonomy (179) since autonomy is understood not only as decision-making in healthcare processes but also as a prerequisite to retain control over physical, social, social and spiritual matters.

Spirituality is also discussed as a coping mechanism for dealing with destabilising situations with particular challenges and a potential mechanism of action (66, 180, 181). It is widely accepted that an existential component of spirituality refers to meaning in life (among others: 25, 29, 182-184). Previous research confirms that meeting the needs in a spiritual dimension through respect, honest conversation, attention to overall well-being, and generally feeling affirmed and valued may be a key aid (19, 185).

Against this background, it seems pivotal to offer interventions that aim to re-evaluate and reconstruct past life trajectories and the actual individual living situation to enhance meaning. A confrontation with end-of-life topics and existential questions is inevitably part of this. Further research is required on how best to approach this sensitive topic in a vulnerable situation and feeling close to death.

## 8.2 How to address needs in confronting the end of life

A challenging life situation due to old age or disease, requires reconstructing and re-evaluation of one's life to fit life events into the actual life (25, 186). A redefinition of one's role in life is part of the process of adaptation. It seems necessary to face limitations in life, including limits of one's own expectations (186). The overlap of spiritual issues with meaning-in-life-interventions leads to the assumption that meaning-in-life interventions can be a suitable form of engagement towards a successful adaptation and therefore increased well-being (136).

Creating meaning in life and accepting the existential givens are interrelated. Therapies and interventions should include both aspects: experiencing meaning in everyday life while affirming the confrontation with the existential givens, e.g., a destabilising situation due to feeling close to death (187). This relation is part of the existing interventions called existential therapies that aim to enhance meaning and decrease distress. Those approaches have their roots in the theories of psychiatrists such as Frankl, Jaspers and Biswanger, and interventions are informed by existential philosophers like Sartre, Buber, Kierkegaard, Nietzsche, Tillich and Heidegger (187). Bauerreiß et al. (134) conducted a meta-analysis of the effects of existential interventions in patients with cancer. The authors understand existential interventions as interventions that create meaning, foster hope or dignity or support people to express feelings and concerns concerning the end of life. This definition includes in any case a confrontation with existential topics. Results indicate short-term effects on improved existential well-being, self-esteem and quality of life.

Most of the evaluated approaches that involve confrontation and are supposed to be meaning-enhancing are based on conversations. Posing existential questions when nearing the end of life is rated positively by around 77% of participants (136). The results of the second paper of this dissertation support these results in that the people included people confirmed that people felt comfortable talking about death and dying even when not expected to do so or when they had been reluctant to talk about end-of-life topics in the past (167). The power of storytelling may enable people to construct or reconstruct their framework of meaning in life (25). A mixture of valuing life, dignity-related questions and addressing end-of-life topics might also be relevant in raising the motivation for higher engagement in end-of-life topics (188). It seems insufficient to only confront concerns and existential issues but also an appreciation of life should also be included (23). According to the concept of double awareness, it is impossible to avoid the awareness of one's own end of life while still engaging in life (189). In the context of searching for meaning when facing the end of life, Wong explains a two-factor model: a negatively orientated search for meaning that addresses existential problems of suffering from the nearing

end of life to understand destabilising events and a positively orientated search for meaning to fulfil the remaining life time (88, 128). The basic assumption that confronting is more fulfilling than avoidance remains (128). Taking this ambivalence into account it is important to integrate aspects of esteem, appreciation and positive outlook and aspects of confronting death-related issues and concerns when providing psychosocial support in confronting the end of life. This statement is in line with the assumption that meaning in life should only be treated in consideration of existential givens (187).

Most of the interventions included in the review of this dissertation consider the conversation as an underlying form of providing support and consider the ambivalence of the topics in terms of including positively orientated questions and questions on existential concerns. Therapy aspects of life reviews are frequently used. This consistency and the positive effects on measures of psychosocial comfort that emerge from the review suggest that these approaches are promising (166). An overlap between spiritual issues with meaning-in-life interventions leads to the assumption that differently-labeled interventions follow the same aim with similar methods (136).

### **8.3 Psychosocial approaches and their confronting content**

The systematic review conducted in this dissertation summarised different approaches and concluded positive effects on psychosocial outcomes. Included approaches were grouped as meaning-enhancing interventions, meaning-centred therapy, educational courses, and experiential learning. The approaches differed in length, thematic focus and method of delivery but all have confrontation content on topics concerning the end of life. Table 2 provides an overview of included interventions and the confronting content.

<b>Intervention</b>	<b>Confronting content</b>
Managing Cancer And Living Meaningfully (CALM) (190-192)	Sense of self and relation with others, sense of meaning, advance care planning
Dignity Therapy (114, 153, 161-163, 193-204)	Life review, meaningful relationships, legacy, generativity
Educational courses (157, 205)	Fears related to ageing and dying, fears about loved ones, preparing for one's own death (funeral, wills, obituary), advance directives
Individual Meaning-centered Psychotherapy (164, 206, 207)	Sources of meaning in life, addressing existential concerns, legacy, hope and finitude of life
Life review interventions (154, 155, 208-218)	Meaning in life, self-identity, legacy, generativity, evaluation of the past, forgiveness, re-evaluation and re-construction of life, and integration of experiences
Outlook (219, 220)	Life story and evaluation (regret and peace), generativity, leaving a legacy, sense of meaning
Soul's Legacy (221)	Reflections on meaningful items, life stories, symbolic items, sharing meaningful tokens with others, coming to terms with one's own end of life
Sharing Patients' Illness Representations to Increase Trust (SPIRIT) (222)	Individual representations of the illness or health problems
Meaning-making Intervention (28, 156, 223)	Contemplating the present situation, life review, understanding of the self, sources of strength, meaning in life, readjustment
Experiential learning (224-226)	Preparing for the end of life, views about the end of life, being a burden, meaningful activities

*Table 2: Overview of interventions included in the Systematic Review*

Two aspects stand out when looking at Table 2: First, out of 49 studies included in the review, we count only three studies that focus on individual strategies to confront one's own end of life while the others evaluate existing interventions. Second, meaning is part of almost all listed interventions.

Since individual experiential learning is underrepresented in research, the interview study was conducted to fill this gap (167). It is striking that the results of the interview study reveal that

people mostly use private contexts to confront end-of-life topics because (semi-)professional existing interventions are not accessible or visible enough. The review, however, shows that individual strategies to confront the end of life are poorly evaluated (166). That leads to two conclusions: First, people nearing the end of life must be aware of where to find support, independent of who provides the support, to be able to have conversations about existential topics like meaning, dignity or relationships (14, 19). Second, it is also highly important to pay greater attention to the needs of those people who are directly affected, i.e., feeling close to death and consequently focusing more strongly on research in first-order perspectives to learn and derive psychosocial support services to confront one's own end of life based on the experiences and perspectives of those people who are affected (11, 165, 227).

Sense of meaning as a key concept seems to be verified in diverse studies and should therefore be an integral part of psychosocial support. The results of the interview study confirm that a confrontation can lead to feeling more meaningful. The participants want direct and accessible offers for discussing existential end-of-life topics and contact facilities, either within a professional context or in a private context (167).

According to a qualitative analysis of end-of-life care, the concept of meaning in life is associated with spirituality and the end of life. Definitions of spirituality often contain meaning in life or the search for meaning as a core component (109). The most common definition of spirituality was developed in a consensus process of the EAPC and is based on the American National Consensus Project for Quality Palliative Care (NCP) (228). "*Spirituality is the dynamic dimension of human life that relates to the way persons (individual and community) experience, express and/or seek meaning, purpose and transcendence, and the way they connect to the moment, to self, to others, to nature, to the significant, and/or the sacred*" (229 p.88). Other authors describe the search and creating meaning as a spiritual process (230) or even as an aim of spiritual care in healthcare settings (231). As mentioned, the concepts of existential needs, to which meaning is also attributed, and spiritual needs are used interchangeably (14, 108, 109). Much of the content of the approaches in Table 2 could be assigned to the spiritual dimension. It is important to filter out which content is profitable for confronting the end of life, rather than which category or dimension the content belongs to.

#### **8.4 Spirituality when nearing the end of life**

Spirituality, as defined in the previous chapter (p.28), is a multi-layered construct (20) and may encompass various spiritual needs, such as a '*need for meaning*', '*need for relationships*', '*need for control*' and '*need for independence*' (17). Spiritual, existential and psychosocial needs are interconnected (232). This implies that people with a religious background would rather

concretise their needs as spiritual, while nonreligious people would categorise those needs as existential or psychosocial (232). Generally, spirituality is shifting from a religious view to a more flexible, existential view (233). According to Tornstam (180), it is seen as an ageing task while aiming for a redefinition of self-identity and therefore working as a coping mechanism (234). Spiritual care gained an important role in healthcare in the last decade with increased interest by healthcare professionals (235). Spiritual care recognises the relationship between a health problem and the spiritual dimension and addresses and supports the search for meaning when existential questions of life and death arise (236). It encompasses spiritual interventions that support another's spirituality by companionship of the individual and developing a mutually agreed plan of care (184).

Hence, spiritual needs gained increasing attention in healthcare, also as a component of whole-person care in practice (6, 66) but are often avoided due to time constraints, uncertainty concerning spirituality and the absence of training on how to meet those needs (14, 149, 237). According to the self-determination theory, the satisfaction of fundamental needs, specifically the needs of autonomy, relatedness, and competence, enable increased well-being and greater levels of motivation. Liu et al. (238) reported higher well-being when spiritual needs were satisfied. However, if fundamental needs remain unsatisfied, this may have a robust inimical impact on measures of well-being (93). Applying this theory to the context of existential and spiritual needs in old age or when terminally ill, Clyne et al. (185) reviewed qualitative evidence and summarised that unmet needs, such as having relationships, managing life, dealing with death and dying and finding meaning, can lead to profound distress and concerns. These manifest themselves symptomatically in terms of loss of sense of self, decreased sense of loneliness and sense of meaning and death anxieties (185). As this form of distress represents an existential threat, some researchers demand that spiritual distress be recognised and handled like a diagnosis equal to physical pain (20, 228). If spiritual needs remain unmet, they can cause distress and suffering that is associated with poorer psychological adjustment and mental health (75, 117, 134, 239-241) and an increase in health service use (6, 22). The patients value healthcare professionals who pay attention to their existential and spiritual needs (239) by treating them respectfully, listening to them, encouraging them, taking their burdens and helping them to find peace (19). They want their physicians to know about their spiritual beliefs to be understood as a person (242). Spiritual problems were mentioned by around 40% of patients with serious diseases (76).

Evidence of spiritual care interventions and related effects on health-related outcomes, especially when taking into account randomised controlled trials, is scarce and to date limited



to patients with life-limiting diseases in palliative care (109). However, initial conclusions that can be drawn from the existing research are summarised in the following.

Spiritual dimensions, e.g., self-identified spirituality, are connected to positive outcomes of quality of life (233). When addressing the spiritual dimension of confronting one's own end of life in a spiritual care setting, positive effects on quality of life, emotional well-being, peace, meaning and hope are reported (25, 238, 243-245). Mutually dependent individuals with an enhanced sense of psycho-spiritual well-being have more successful coping strategies and lower levels of distress when facing life-limiting diseases (107, 134). Addressing spiritual needs is even connected with successful ageing (87).

Spiritual interventions such as meditation, reading sacred texts or praying, contemplative exercises, narrative interventions and storytelling are reported to have positive impacts on the patient's quality of life (25, 219) and can ease symptoms of distress (218). Balboni et al. (244) reported on the association between greater spiritual support in terms of spiritual care and higher scores of quality of life when compared with patients who did not receive spiritual care. Scores increased by 28% on average when nearing death. It is noteworthy, that the effects of spiritual care did not depend on the medical caregivers, e.g., nurses or doctors and chaplaincy medical caregivers or pastoral care providers addressed corresponding needs (244). Addressing spiritual needs is critical in healthcare settings in enhancing psychosocial well-being and should be treated with the same importance as physical symptoms (233).

As mentioned, spiritual needs are often neglected in healthcare for several reasons: 1) Due to a lack of training, healthcare providers do not feel comfortable assessing spiritual issues and providing spiritual care (19, 30, 109, 145, 183, 184, 228, 240, 246). 2) Healthcare providers have different role expectations that do not include addressing spiritual questions (19, 183) and sometimes feel an undesirable power inequity with the patient (183). 3) The lack of time in healthcare settings is often mentioned as a barrier and an inappropriate environment to address sensible content (19, 184, 240, 246). 4) Personal discomfort with the topic may also be a constraint (19, 184, 246). 5) The lack of research and the lack of a shared language cause insecurity in dealing with spiritual issues (228, 247). 6) Other reasons like a lack of initiative from the patient (236) or a lack of interprofessional collaboration (228) may inhibit the provision of support.

The patient's view of barriers to spiritual care differs partly from the perceived barriers of healthcare providers. Internal factors include: 1) Patients avoid deep topics to maintain hope or a positive outlook. 2) Some patients state that they do not perceive the need for additional help because they feel supported by family and friends. 3) A reluctance is reported due to not having

a concept of spirituality or spiritual care. External barriers to receiving spiritual care include: 1) A disease-orientated view of the patient and unawareness about the availability of support keep them from initiating spiritual care. 2) Professionals lack training and doubt that they could help to cope with issues. 3) Time constraints and the lack of privacy in most healthcare settings do not allow for spiritual conversations (248).

After summarizing the evidence on spirituality in healthcare and relating the concept of spiritual care to confronting one's own end of life, few frameworks have gone beyond comfort and quality of life to define outcomes of care. While exploring the needs when nearing the end of life, it is crucial to consider spiritual, functional, psychological and physical domains. Exploring the needs and confronting existential questions about life and death can ease distress and even enable personal growth (21, 23, 165).

The general attitude towards non-physical needs, be they existential, psychosocial or spiritual, is of great importance for those who feel close to death due to disease or old age. In the framework of whole-person care (20, 66), spirituality is an integral part. An appreciative attitude towards spiritual issues is described and perceived as having a great effect on psychosocial comfort. Consequently, it is twofold: 1) Interventions that focus on confronting existential issues of life and death are highly important in increasing well-being at the end of life. 2) The setting and attitude created when confronting existential issues should be guided by principles of spiritual care that create a compassionate environment (66, 119). The integration of spirituality in healthcare settings induces whole-person-centred care with recognition of human dignity (66). Koslander stated (243), "*if a patient's existential and spiritual needs, like physical needs, are seen as resources that are to be taken into consideration in health care, then a holistic care approach can be developed*" (p.34).

To meet the needs of people feeling close to death and confronting their own end of life, it is essential to recognise that beyond the awareness of psychosocial needs and offering appropriate interventions, care that is guided by spiritual values, particularly compassion, honest conversations and respect (22, 184, 185).

### **8.5 Derived characteristics for future approaches**

The results of the discussion are addressed in the light of other studies to further explore the meaning and identify the importance of the data for practical application.

The urgent need for psychosocial support to minister the existential issues when nearing one's own end of life is undeniable. Existing approaches aim to decrease distress and anxiety and increase well-being and quality of life and are evaluated positively by recipients (28, 166).

Individual strategies for coping with existential challenges and confronting one's own end of life have been little researched and the opportunities to derive new forms of interventions from this first-order data are hardly used (44, 165). Meaning is discussed to be a mechanism of action in support services that enables adjustment to new situations and coherent integration of the current situation into their lives (21, 128). The concept of meaning in life and aspects of spirituality and spiritual care overlap, and spiritual needs are frequently reported, sometimes interchangeably with existential needs, in the concomitant consciousness of impending death. Profound despair can arise when spiritual needs are disregarded (20, 66). The following aspects should be considered in delivering psychosocial support to increase outcomes of psychosocial well-being:

- a) Content: Confronting end-of-life issues that might also be negatively associated and aspects of esteem, appreciation and positive outlook should be integrated (23, 128).
- b) Methods: An honest, compassionate and empathetic conversation should be used to encourage storytelling (22, 145, 184, 185). Spiritual sensitivity helps treat people who are striving for wholeness amid of profound vulnerability to meet their needs (249).
- c) Provider: Many people want their caregiver to consider existential needs (242), but support can be provided by anyone (185).

The demographic change and the resulting aging population will reduce the potential of families and informal caregivers for adequate care at the end of life and demand care work from (semi-professional) healthcare systems at the end of life. This leads to several practical implications.

## **9. Implications**

### **9.1 The relevance of rethinking care at the end of life**

The opportunity to confront existential questions when facing one's own end of life should become an area of greater focus within whole-person care. The outlined discrepancies between existing psychosocial support in the care system when nearing one's own end of life and the preferences of people with serious diseases or in old age indicate a need for action on several levels (10). Against the background of knowledge about demographic change and its challenge in end-of-life care, urgent changes in healthcare become obvious. Society needs to discuss opportunities to enable well-being until late life. Sociological and gerontological approaches should be considered to define implications for practice, theory and policy.

Research shows indisputably that psychosocial, existential or spiritual needs come to the fore as people approach the end of life (14, 134, 167). Research also shows that interventions exist that address these needs and have a positive impact on measures of psychosocial comfort (28, 166, 250) but are rarely used due to impediments to access in a complex and fragmented health system (167). The psychosocial support options are better established in palliative care, but people in old age who feel close to death due to ageing processes and related losses also report existential issues and a desire for low-threshold, accessible and flexible services to meet their existential and spiritual needs (167). The intersection of existential issues with spiritual issues leads to the concept of spiritual care, which also addresses existential issues and describes an inner attitude of the provider that has a positive impact on well-being and quality of life (134, 183, 244). Elaborating on the effects of confronting one's own end of life in this dissertation, the concept of spiritual care covers a large part of the need for confrontation and provides a suitable framework for confronting existential issues of life and death.

New concepts of care should be developed that interlink geriatric and palliative care more closely and provide offers for psychosocial support to help people minister the existential issues at the end of life. On the other hand, efforts to raise awareness for psychosocial and spiritual support should be increased and new concepts for psychosocial support should become an integral part of our healthcare system. To achieve that goal, an integrative approach throughout societal structures, including related policies, adequate access to support services and education of healthcare providers and the public is required (251).

### **9.2 Collaboration between geriatric and palliative medicine**

The similar existential needs of people in old age and people with life-limiting illnesses point to a closer interaction between geriatric and palliative medicine (167). Psychosocial support

systems are better developed in palliative medicine but are equally important in other healthcare settings (252). Working practices and shared objects of work form an intersection between geriatric and palliative medicine and have a common ground: They are goal-orientated and based on individual preferences with a clear focus on psychosocial factors (253). However, an interaction of the areas is still under-researched and under-developed, though improved care work at the end of life could be a likely outcome (254). An integrated care approach to healthcare could be a determinant to better address the easily overlooked spiritual distress (251). Voumard et al. (255) state, “*we need an integrative approach that zooms out to the global picture of the patient’s life situation*” (p.3). A Delphi consensus process has shown that European care professionals agreed that palliative care principles, including spirituality, should be integrated into geriatric medicine. Thus, the statement about understanding the nature of spirituality, recognising the spiritual dimension of people and creating a safe space for addressing spiritual needs reached 90% agreement (251). To assure a continuity of care an individual usually needs access to more than one health system service and the information flow might be decisive for meeting the varying individuals’ needs (256). Care processes should be coordinated to develop an accessible and flexible interface between services (257).

### **9.3 Implementing assessments and interventions in healthcare routines**

To implement a coordinated, transferable support healthcare system, concrete changes in the organisational structure are needed. The EAPC sees a necessity in specialists for spiritual care coordination and psychosocial support (84). Role relations and boundaries of interprofessional work are often unclear. A coordinated care system that encompasses routine screenings for existential and spiritual distress could recognise people without realising that the root of their concern might be a spiritual issue, and support can be considered (19, 253, 258). Other researchers propose establishing a spiritual health coordinator or a spiritual care team to carry out diagnostics, coordinate care structures and initiate referrals when needed (6). Systematic integration of a coordinating role may act as a booster in achieving successful intersectoral communication and care (259). Koenig (6) stated that a spiritual care team, consisting of a spiritual care coordinator and a physician or therapist, whose tasks are to identify and address potential spiritual needs, create an environment to initiate a conversation and advocate these whole-person needs with healthcare providers.

First, assessments or screenings are necessary to identify needs. Heyland et al. (98) suggest an individualised quality of life assessment. The patient’s desire for assessing spiritual needs indicates regular assessment of needs as a fixed component of care (260) using a socio-spiritual assessment tool or a questionnaire for person-centred orientation (17). Koenig (6) propose a

spiritual history to elicit a social history including sources of support and coping resources. Research results indicate that taking a spiritual history can relieve from symptoms of existential distress and that taking a spiritual history can relieve symptoms of existential distress (246). In a randomised trial, healthcare providers stated that after taking part in the Holistic care program for elderly patients that aimed to integrate spiritual needs, social activity and self-care into disease management in primary care (HoPES3) their awareness of the individual's spirituality was increased. Participants reported on benefits and resulting resources from taking a spiritual history: the insights into the individuals' life allowed for a deeper understanding of the behaviour and a better physician-patient relationship (261).

Second, besides a greater focus on assessing distress, low-threshold counselling services for existential and spiritual issues should be implemented (250, 262). An increased focus on conversations about one's own end of life is a prerequisite to planning interventions that are adapted to individual needs and preferences. Therefore, individualised conversation tools should be systematically offered (104). Some people have become withdrawn due to not being relevant and fear of asking for support (20). Hence, the desire for active initiation by care staff is preferred to the patient's initiation (30).

An example of implemented principles in addressing existential and spiritual needs is the national guideline on spiritual care in the Netherlands, which has anchored existential support in every discipline (30). Another example of international guidelines that address spiritual needs within the concept of whole-person care is the Australian National Guideline for Spiritual Care in Aged Care, which aim to support organisation to embed spiritual health into key processes to offer best-practice models (123). In Germany, however, spiritual and psychosocial support systems need to be considered in healthcare routines more firmly. Developing a guideline to provide concrete and tangible ways in creating an environment to confront existential and spiritual topics may be a meaningful implication (20).

#### **9.4 Carers' attitudes**

Assessing the existential and psychosocial needs of people nearing the end of life and providing care require an awareness and familiarity with the existential guidance of the carer (262). This applies to both family carers and professional carers. An unguided sensitivity to the individual's concerns facilitates an existential and spiritual understanding (243). To show interest in the individual concerns and attitudes and to value the people with their attitudes, concerns, hopes and fears it is crucial to listen to them and initiate support by posing a simple question like: 'How can I help you?' (20). '*Presence*' can be a key aid in encountering (14). Principles of being present include a compassionate, empathic, affirming and warm therapeutic attitude (22)

to enable genuine care and an honest relationship (185). Small gestures such as addressing people by their names, smiling at them and listening respectfully can pave the way to compassionate care (185). The relationship is the essential criterion within a care setting based on whole-person care (14). Still, it can be a balancing act between alleviating loneliness through initiating conversation or leaving people alone who want to be left alone (30). However, healthcare professionals mentioned diverse barriers to feeling comfortable when providing psychosocial care. The abovementioned main barriers are a lack of guidelines and unclear role expectations, lack of time and a lack of training and education (19, 78, 109, 183).

### **9.5 Training and education**

For a rethought end-of-life care system that meets the existential and spiritual needs skills are required that go beyond the medical and nursing skills (14). Hence, training for health professionals and mandatory courses on how to deal with patients in life crises or the end of life on a psychosocial level should be implemented in the education curricula (66, 109, 145, 263, 264). Fostering the matching between patients' needs and healthcare professionals' competencies in psychosocial support should be seen as an integral part of the healthcare role, not as a special add-on (108, 265). A German survey revealed the importance of spiritual and existential topics being integrated into the curricula of medical schools. Some of these medical schools offer content on existential and spiritual care, but not as a mandatory subject, whereas spiritual care is not specifically integrated in German universities (265). Hodge et al. (112) also concluded a paucity of educational training. Even in palliative care professionals are not trained in end-of-life issues including autonomy, meaning, dignity, relationship and addressing existential issues (14).

Training and reform of education should include a scope of practice that enables raising awareness of non-medical needs and assessing and encountering existential needs holistically (20, 145). More precisely, competencies should be expanded in the following areas:

- 1) A language to expand the gaze for existential concerns and to ensure a mutual understanding (21, 247)
- 2) Engaging spiritual resources in coping with concerns at the end of life (245)
- 3) Fundamental skills in assessing or screening, e.g., eliciting a spiritual history (20, 66, 260, 263)
- 4) An understanding of one's own spirituality (66, 265)
- 5) Basic skills of treatment and treatment planning (263)

## 6) Recognition when spiritual issues become a diagnosis and referral (20)

Therefore, while effort focused on the needed skills set is required, research results to inform curricula and training are still pending (20). The feasibility of reforming curricula and implementing trainings cannot yet be determined due to the limited number of pilot projects so far. Taverna et al. (265) propose that a four-hour teaching program within undergraduate medical education can be sufficient to improve the students' competencies in spiritual care.

The following is an overview of evaluated programmes: An evaluation of training of multipliers called Interprofessional Spiritual Care Education Curriculum (ISPEC) revealed that the training for interprofessional spiritual care was successfully implemented in different institutions. Assessing concerns, a compassionate presence and conversations about issues contributed to implementing new standards and a system change within healthcare. The course increased the self-efficacy of healthcare professionals in taking leadership in spiritual care (266).

Eliciting a spiritual history with older patients was evaluated in the HoPES3 program. General practitioners and medical assistants considered the method helpful and felt less inhibited in starting spiritual conversations. The relation to the patient was subjectively strengthened with the opportunity for better treatment adherence (261). The same program was evaluated focusing on the application of learning objects, and general practitioners and medical assistants stated that they learned how to address spiritual needs and implement the knowledge into everyday clinical routines (267). As a pilot project to reform medical curricula, a workshop was designed for students from medicine, social work, and chaplaincy to learn about spirituality, spiritual care and interprofessional spiritual assessments. The workshop was perceived as highly useful and allowed reflection on one's attitudes (264).

Most healthcare professionals received no training, though the strongest predictor of providing spiritual care by nurses and physicians was the reception of appropriate training (240).

### **9.6 Society and community**

The changes in the age structure described above represent a major challenge for the health system. An overburdened healthcare system may be compensated by developing and implementing new civil structures to meet the needs at the end of life. People nearing the end of their lives want to exchange views on existential issues in a private context (167). Those who have a well-functioning social network are privileged, but the burden on relatives may be high, nonetheless. Those who do not have family members or are connected to communities may withdraw from the world (8). Community engagement and understanding how to actively contribute to a socially inclusive health system require thinking across organisational and



community boundaries (268). The necessity for an integrated social care system is evident but often unavailable (269). Mechanisms of change should be made in different areas:

*Public awareness:* Building awareness not only on a political level but also on a societal level is an important public health and societal issue. An open exchange about death-related issues should be promoted. Open discussion groups at the community level could be a starting point. Relevant organisations in end-of-life care should foster public relations and raise awareness about well-being at the end of life. The media can be used to raise awareness of issues such as advanced care planning (115).

*Practical support:* Supportive forums, networking and educational events can help to rethink social support at the end of life. The aim should therefore be to enable the community, e.g., families, neighbours and organisations, to identify the problem in end-of-life care and determine priorities for action (66, 268). A basic requirement is building ‘Death Literacy’, which means promoting knowledge, a sense of empowerment and practical skills to actively build up social structures to support caring for those nearing the end of their lives (270).

*Compassionate communities:* Compassionate communities are defined as “*communities that develop social networks, social spaces, social policies and social conduct that support people through the many hours, days, weeks, months and sometimes years of living with a life-threatening or life-limiting illness, ageing, grief and bereavement, and long-term care-giving*” (271 p.xiv). In this social model of care, caring for people nearing the end of their lives at home becomes a plausible scenario (272).

*Volunteering:* Volunteers, whether formal or informal, are an asset to caring communities. More efforts are required to recruit, train, value and connect volunteers into a more integrated organisation to support people, their families and communities locally and nationally (269).

## 9.7 Research

To ensure a better response for meeting spiritual and existential needs when nearing the end of life and to motivate policymakers, providers, community stakeholders and the public to action to improve end-of-life care services, the evidence base must be strengthened. Therefore, professionals, non-professionals, volunteers and any kind of providers in end-of-life care should contribute and participate to collect robust data. To date, research is often service-orientated instead of person-orientated (273).

Further research focusing on confronting the end of life is needed to investigate the individual perspectives on confronting one’s own end of life to provide a basis not only for the content design of programs and interventions but also for the appropriate choice of methods, timing,

duration, acceptability frequency of interventions (8, 39, 145). Participatory work is rarely the focus of research and unseen opportunities remain, which means that people facing the end of life should be directly involved in research (8). Funding priorities should therefore follow social health priorities with an emphasis on well-being science (272). The implications mentioned in the previous chapters are equally important and mutually dependent. Above all, research on well-being should more often be the subject of research to put debates on ageing well on the political agenda and broaden the focus on whole-person care to include existential support and guidance (262).

For theoretically underpinned interventions and support services, further elaboration on the mechanisms of action and ascertaining their long-term effectiveness is obligatory (8). With the evaluation of pilot projects that aim to implement new models of health focusing on interdisciplinary holistic care, further modifications can be suggested to drive implementation processes and a rethought curriculum for healthcare professionals (267). Research on healthcare providers' self-reflective responses to existential distress could contribute to building an awareness of one's own presence when accompanying a person who feels close to death and inform proper training programs (14, 21).

## 10. Strengths and limitations

### 10.1 The semantics of used terms

The results of this dissertation must be viewed in light of strengths and limitations and have been discussed in the respective articles (166, 167). In the following, overarching methodological issues of the dissertation project will be addressed.

For this dissertation, the vocabulary is intentionally chosen, though definitions of the focus ‘*confronting one’s own end of life*’ are lacking. The working definition is based on the existing literature; it is nevertheless understood differently in other studies and therefore a direct comparison with other research requires prior clarification of the definitions used. The semantic concepts of the terms *existential* and *spiritual* that are used are contestable in that researchers sometimes used these synonymously and sometimes a strict separation was recommended (14, 20). Based on existing primary literature, the terms have been defined in this dissertation, but room for interpretation remains. *Existential* and *spiritual* were used as coexisting and therefore frequently used in one sentence to cover both concepts and to address those people who only draw upon religious ascription when talking about spirituality.

The outcome measures chosen in the review, which summarise the effects of confronting one’s own end of life, were classified inductively based on the data of the included studies. A different classification and naming of categories could have been made by orienting the categories towards theory-based literature on needs at the end of life. Hence, it would have been possible to integrate the self-determination theory explained in Chapter 8.4, or the sense of coherence model summarised in Chapter 8.1 could have been more strongly integrated into the review (93, 176). The basic need for autonomy, which is often used synonymously with self-determination, is one of the central concepts that essentially determine well-being at the end of life (274, 275) and under which some of the outcome categories defined could have been classified. For reasons of practicability, a more theory-based category identification was not used but integrated within the overarching interpretation of research in this dissertation.

### 10.2 Choice of methods

A strength of the review is its inclusivity, including heterogeneous study designs and therefore providing a comprehensive research overview. The meta-summary method enables a synthesis of study results from all types of studies and explores the depth of phenomena (172). Though a rigorous process was followed in retrieving the studies, the exclusion of eligible studies cannot be ruled out. To address this limitation, a forward and backward citation tracking of included studies was conducted. The distribution of countries of the included studies gives a broad

picture of the effects of confronting, but on the other hand, cultural background and practices are not considered. A full range of practices and approaches to confronting one's own end of life in different cultures would be needed to generalise the findings. The imbalance toward terminally ill persons due to a lack of research targeting people in old age also contributes to the fact that the results cannot be generalised. Otherwise, the analyses and results must be limited to the respective cultural environment and interpreted with cultural sensitivity to the given location. An information bias due to the exclusion of studies written in languages other than English or German and a publication bias due to the tendency to publish mainly desirable results are conceivable.

The qualitative research design of the second article was chosen to generate explanatory hypotheses and should contribute to reducing the deficit of qualitative studies on care at the end of life (11). The open nature of the interviews and the open space for contemplating sensitive topics made participants feel comfortable despite the emotional strain. Participants were selected purposefully to yield rich information on needs, desires and experienced effects of confronting one's own end of life from a first-order perspective (276). Since participants were fully informed regarding the aim and context of the interviews it can be assumed that the sample consisted of people who felt comfortable talking about death-related topics they would be asked to elaborate on and therefore might be biased. Since the concept of bias is criticised for not being applicable in qualitative research (277) the results of the interview study should not be regarded as less valid, but the transferability of results might be limited to similar contexts.

A valuable feature of this dissertation and its focus on data from a first-order perspective, i.e., focusing on the perspectives and attitudes of those directly affected. In particular, the oldest old remain largely underrepresented in research and health promotion on care at the end of life (2). As such, the methodological approach was person-centred, with its results contributing to the development of supportive care of existential concerns through confronting issues of life and death.

## 11. Conclusion

This dissertation aimed to provide valuable insights into how people nearing their own end of life due to life-limiting disease or old age confront death-related topics and how confronting may affect measures of well-being. Wishes to confront one's own end of life can inform support services to better meet people's needs.

People who feel close to death usually experience existential issues that may result in a lack of coherence and orientation. A process of psychological adjustment to self is required to maintain or reach psychosocial well-being. In that process of adjustment the confrontation of death-related issues might be an important determinant. Approaches and interventions are diverse. The conclusions that can be drawn from the dissertation show both positive effects of using (semi-)professional existing interventions, which are little used in Germany, and applying individual strategies of confrontation. Offers and visibility for addressing existential questions or even the treatment of existential suffering are rare but are increasingly desired by people who are nearing the end of life. To meet people's needs, existing interventions should be revised, new interventions need to be developed and implemented, and most importantly, interventions must be made visible and accessible. Professional and informal support frameworks that organise screening, interventions and referrals need to be anchored in the health system. A change of mindset of care providers is required to create contexts in which confrontational issues are addressed in the context of compassionate care. Research results indicate that in addition to confrontational content, aspects of esteem and appreciating and valuing the life lived are equally important to positively influence psychosocial comfort. Meaning in life is a key term and a central mechanism of action in the discussion and the context of spiritual care that covers a wide range of existential needs of people at the end of life.

Following the results of this dissertation, more effort must be put into researching existential needs and reforming curricula for training and education for health and social care providers and creating an awareness of existential issues to ensure compassionate support of existential themes and relational care. Furthermore, the importance of confronting one's own end of life and its effects on well-being should be discussed more often. The vision of approaching the end of life in a resource-orientated way and understanding existential health as part of the various dimensions of health could be part of the answer to the question of how we can face the ageing society with more confidence. Confronting death-related issues can be seen as a social concern, and responsibility through a broad social movement may contribute to existential well-being.

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## **Doctoral student's declaration of contribution**

**1. Kukla H, Herrler A, Strupp J, Voltz R. The effects of confronting one's own end of life on older individuals and those with a life-threatening disease: A systematic literature review. Palliative medicine. 2021;35(10):1793–814**

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Helena Kukla coordinated the project and conducted the search for eligible studies. Helena Kukla and Angélique Herrler conducted the screening of the studies to be included and critically assessed the included studies. Helena Kukla analysed the included studies in cooperation with Angélique Herrler. Helena Kukla prepared the draft manuscript. Helena Kukla revised the manuscript in cooperation the other authors and all the authors consented to the submission of the manuscript.

**2. Kukla H, Herrler A, Strupp J, Voltz R. "My life became more meaningful": confronting one's own end of life and its effects on well-being-a qualitative study. BMC palliative care. 2022;21(1):58**

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All authors (HK, AH, JS, RV) contributed to this manuscript in terms of its conceptualization, methodology and editing. Helena Kukla was responsible for the provision of participants and data acquisition. The Data analysis was conducted by Helena Kukla in cooperation with Angélique Herrler. The interpretation of the data was taken over by Helena Kukla and checked by the other authors. The Manuscript writing was done by Helena Kukla and all authors revised the manuscript and contributed to the final approval. All the authors participated sufficiently in the work to take public responsibility for the appropriate content.



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## Curriculum Vitae

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### Werdegang

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Seit 01/2018	<b>Honorar-dozentin</b> Hochschule Döpfer (Standort Köln)
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02/2012 – 12/2013	<b>M.Sc. Lehr- und Forschungslogopädie</b> Rheinisch Westfälische Technische Hochschule Abschlussnote: 1,2 Auszeichnung: Springorum Denkmünze
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**Tätigkeit als Reviewerin**


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2021	Würdezentrierte Therapie – Grundausbildung (20 h) Deutsche Gesellschaft für Patientenwürde e.V., Mainz
2021	Summer School “Empirical Approaches in Aging Research” (40 h) Universität Vechta
2020	Fortbildung “Project management for scientific project managers” (8 h) Universität zu Köln
2019	Summer School “Qualitative Research Methods in Health” (40 h) University of Antwerp, Belgium
2019	Summer School “Making Systematic Literature Reviews work for you” (40 h) Radboud University, Netherlands

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---

10/2021	Workshop im Rahmen des Projektes resistdance in den Ehrenfeldstudios zum Thema Alter(n) und Rassismus
12/2019	Wissenschafts-Praxis-Kollegtagung: Organisation und Durchführung

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12/2022	Podcast-Folge für knowlAGE zum Thema “Promovieren in der Gerontologie”
Seit 2013	Ehrenamtliche Tätigkeit als Sterbebegleiterin im Hospiz St. Marien in Köln
04/2021	Radiobeitrag WDR 5 Neugier genügt: „Wie Ältere mit der eigenen Endlichkeit umgehen“

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**Fachartikel in Erstautorinnenschaft (peer-reviewed)**

1. **Kukla H**, Herrler A, Strupp J, Voltz R. “My life became more meaningful”: A qualitative study on the effects of confronting the own end of life from the perspective of people aged 80 and over and people with a life-limiting disease. *BMC Palliative Care*. 2022; 21, 58.  
<https://doi.org/10.1186/s12904-022-00950-3>.

IF\*

5.7

2. **Kukla H**, Herrler A, Strupp J, Voltz R. *The effects of confronting one's own finitude in old age and terminally ill people: A systematic literature review*. Palliative Medicine. 2021; 35(10): 1793-1814. <https://doi.org/10.1177%2F02692163211042528>. 3.1
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5. Strupp J, Valerius L, Herrler A, **Kukla H**, Eichberg S, Schulz-Nieswandt F & Voltz R. *I see the high interpersonal support during the pandemic as proof that the good in people prevails”: The COVID-19 pandemic as a catalyst for building a caring community? A qualitative online survey*. Journal of Public health (under review). 5.06

\*Stand: Mai 2023

#### Weitere Veröffentlichungen

6. **Kukla H**. Die Auseinandersetzung mit der eigenen Endlichkeit und die Auswirkungen auf das subjektive Wohlbefinden. ProAlter. 2021; 1/21.
7. **Kukla, H.**, Strupp, J & Voltz, R (in Druck). Konfrontation mit der eigenen Endlichkeit. Psychotherapie im Alter.

#### **Präsentationen**

##### Vorträge und Workshops:

*Die Auseinandersetzung mit der Endlichkeit des eigenen Lebens*. Vortrag im Rahmen der GROW Wissenschafts-Praxis-Kollegtagung. Köln. 16.12.2019.

*Die Auseinandersetzung mit der Endlichkeit des eigenen Lebens*. Workshop im Rahmen der GROW Wissenschafts-Praxis-Kollegtagung. Köln. 16.12.2019.

*Die Auswirkungen der Auseinandersetzung mit der eigenen Endlichkeit bei älteren und lebenslimitierend erkrankten Menschen: Eine systematische Literaturübersicht*. Vortrag gehalten auf dem 13. Kongress Deutschen Gesellschaft für Palliativmedizin (DGP). Sine loco [digital]. 09.09.2020.-12.19.2020.

##### Posterbeiträge

*Auswirkungen der Auseinandersetzung mit der eigenen Endlichkeit bei alten Menschen und lebenslimitierend erkrankten Menschen: Eine systematische Literaturübersicht*. Poster vorgestellt auf dem Deutschen Kongress für Versorgungsforschung (DKVF). Sine loco [digital], 30.09.-01.10.2020.

*The effects of confronting one's own finitude in old age and terminally ill people: A systematic literature review.* Poster vorgestellt auf dem World Research Congress online of the European Association for Palliative Care (EAPC). Sine loco [digital] 07.10.2020-09.10.2020.

*Confronting Finitude from the Perspective of People Aged 80 and over or with a Life-limiting Disease: A Qualitative Study.* Poster vorgestellt auf dem World Congress online of the European Association for Palliative Care (EAPC). Sine loco [digital] 06.10.2021-08.10.2021.

*Die Auseinandersetzung mit der Endlichkeit des eigenen Lebens: eine Interviewstudie zu Perspektiven und Wünschen lebenslimitierend erkrankter sowie hochaltriger Menschen.* Poster vorgestellt auf dem Nationalen palliative care Kongress Schweiz: Biel, 24.11.2021-25.11.2021.

*Die Auswirkungen der Auseinandersetzung mit der eigenen Endlichkeit auf das Wohlbefinden.* Poster präsentiert auf der Geriatriisch-gerontologische Online-Konferenz der DGGG e.V. Sine loco [digital], 03.09.2020 – 05.09.2020.

*Die Auswirkungen der Auseinandersetzung mit der eigenen Endlichkeit auf das Wohlbefinden.* Poster präsentiert auf der gemeinsamen Fachtagung „(Neue) Lebensformen im Alter“ der Sektionen III und IV der DGGG e.V. Sine loco [digital], 16.-17.09.2021.

## Lehre

Semester	Titel	Format	Studiengang	Stunden
WS 2022	Reflektierte Praxis in Geriatrie und Psychiatrie	Asynchrone digitale Veranstaltung	B.A. Medizinpädagogik, Hochschule Döpfer, Standort Köln	3 SWS
SS 2018, SS 2019, SS 2020, SS 2021, SS 2022	Reflektierte Praxis in Geriatrie und Psychiatrie	Digitale Veranstaltung / Veranstaltung in Präsenz	B.Sc. Angewandte Therapiewissenschaften, Hochschule Döpfer, Standort Köln	3 SWS
WS 2021	Reflektierte Praxis in Geriatrie und Psychiatrie	Digitale Veranstaltung	B.Sc. Angewandte Therapiewissenschaften, Hochschule Döpfer, Standort Köln	3 SWS
WS 2020 + WS 2021	Forschung in den Therapiewissenschaften	Digitale Veranstaltung	M.A. Medizinpädagogik, Hochschule Döpfer, Standort Köln	3 SWS
WS 2018 + WS 2019	Evidenzbasierte Praxis	Veranstaltung in Präsenz	B.Sc. Angewandte Therapiewissenschaften, Hochschule Döpfer, Standort Köln	3 SWS

## **Publication 1**

### **The effects of confronting one's own end of life on older individuals and those with a life-threatening disease: A systematic literature review**

Helena Kukla, Angélique Herrler, Julia Strupp, Raymond Voltz.

Palliative Medicine 35 (10), 1793–1814 (2021). DOI: 10.1177/02692163211042528.

Two-year journal impact factor at the time of publication: 5,713

# The effects of confronting one's own end of life on older individuals and those with a life-threatening disease: A systematic literature review

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Helena Kukla<sup>1,2</sup> , Angélique Herrler<sup>1</sup>, Julia Strupp<sup>2</sup>  
and Raymond Voltz<sup>2,3,4,5</sup>

## Abstract

**Background:** Awareness of the impending end of one's life can pose profound existential challenges, thereby impairing well-being. Confronting one's own end of life may be an approach to meet the psychological needs and consequently enhance overall well-being. Different approaches of confrontation have been evaluated positively using measures of psychosocial comfort. To date, there exists no systematic overview on the different ways of confrontation (e.g. psychosocial or individual coping approaches).

**Aim:** To synthesize the existing knowledge on the effects of different approaches of confronting one's own end of life on older individuals and those with a life-threatening disease.

**Design:** A systematic review of quantitative, qualitative, and mixed-methods full research reports was conducted. The retrieved studies were screened and appraised for methodological quality by two independent reviewers based on MMAT and CASP. The findings were synthesized narratively using the meta-summary technique by Sandelowski and Barroso.

**Data sources:** Medline, PsycINFO, and Web of Science were searched from inception to 12/2020.

**Results:**  $N = 49$  studies reported on different approaches of confronting one's own end of life, including psychosocial interventions, meaning-enhancing approaches, educational programs, and learning from lived experiences. The results suggest a clear trend toward beneficial effects on psychosocial comfort (e.g. anxiety, sense of meaning, well-being).

**Conclusion:** Low-threshold opportunities of confrontation have the potential to improve well-being and should be emphasized in practical implementation. The results can serve as a comprehensive basis for future research aiming to investigate the determinants of psychosocial comfort for people nearing the end of life.

## Keywords

End of life, well-being, quality of life, palliative care, coping, attitude to death, psychosocial outcomes, review, old age, terminally ill, finitude, mortality

### What is already known about the topic?

- Awareness of one's impending death can lead to existential distress, thus impairing psychological comfort and general well-being.
- Psychosocial support as an emerging need can alleviate symptoms of distress and enhance well-being.
- Research on behavioral and mental confrontation with one's own end of life and its effects on measures of psychological comfort is limited.

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**What this paper adds?**

- Evaluated approaches of confronting the own end of life can be grouped into psychosocial interventions, meaning-enhancing interventions, educational courses and experiential learning.
- The effects of evaluated approaches show a clear trend toward an increase in well-being and a decrease in anxiety and depression.
- Low-threshold opportunities that fulfill psychosocial needs beyond medical treatment and focus on confronting end of life should be implemented.

**Implications for practice, theory, or policy?**

- The opportunity to confront the end of life and address existential questions should become an area of greater focus within patient-centered care.
- The variety of approaches of confronting the end of life and their effects need to be investigated, as do the underlying mechanisms of action.
- In light of the scarcity of actual evidence, the focus should be particularly on individual coping strategies.

**Introduction**

The feeling of being close to death typically arises as the result of natural aging processes or a life-threatening diagnosis.<sup>1–3</sup> Facing death, coping with losses, and coming to terms with the past can call attention to the own end of life. According to the Terror Management Theory, this awareness can ensue as a trigger to making life unbearable, and may increase a person's vulnerability to anxiety.<sup>4,5</sup> Being directly confronted with one's own death is one of the most difficult challenges in life.<sup>6</sup> It is associated with existential concerns and psychological distress, which are commonly defined as symptoms of anxiety and depression,<sup>7–10</sup> and consequently impairs the person's well-being.<sup>11</sup>

As such, the final phase of life is characterized by psychosocial supportive needs that go beyond physical comfort and medical treatment.<sup>3,7</sup> Several factors have already been examined and found to increase life satisfaction and help to ensure a good death, for example, acceptance of the finitude of life,<sup>6,12–14</sup> feeling prepared for dying,<sup>14–17</sup> and a positive outlook on the life lived.<sup>18–20</sup> Providing psychosocial support in a personalized care context in order to fulfill the individual needs of those nearing the end of life can improve their well-being. However, empirical investigations of how to create the conditions for emotional support remain scarce.<sup>21,22</sup>

Confronting finitude means actively facing the existential challenges of the intimidating perception of one's own end of life, for example, the consciousness that life must end in death.<sup>1</sup> It comprises cognitive and behavioral actions that aim at coping with the demanding situation and achieving psychological adjustment.<sup>1,23</sup> Directly confronting finitude of life may be a partially controllable characteristic within the last phase of life,<sup>11</sup> and may enable personal development.<sup>18</sup> Processes of adaptation help to progress toward an accepting and hopeful outlook, whereas a dysfunctional approach to adaptation and a refusal to accept the finitude of life will increase suffering and distress.<sup>6,24,25</sup>

Consequently, the following questions arise: (1) Which existing interventions and/or approaches already incorporate these findings? (2) How do they contribute to well-being at the end of life? To date, research into behavioral and mental confrontation has been limited, especially for those whose need is of critical urgency due to their proximity to death.<sup>4,6,10</sup>

Recent meta-studies have mainly focused on specific single psychosocial interventions, such as dignity therapy<sup>26</sup> and life review.<sup>27,28</sup> These studies have found beneficial effects on psychosocial and existential outcome measures such as depression, anxiety, quality of life, and sense of dignity. Further reviews on meaning-in-life interventions and educational programs support these results.<sup>29–31</sup> Beyond this, several primary studies affirm the positive effects these interventions have on depression, anxiety, and life satisfaction, and also on giving a confident outlook on a good death after preparing for dying using methods such as advance directives and practical knowledge, including skills and experience in end-of-life topics.<sup>32,33</sup>

Aside from this, there has been little attempt so far to compare different approaches of confronting finitude and their respective effects. In a descriptive review on different psychosocial interventions, Teo et al.<sup>34</sup> listed a variety of intervention types that were most commonly effective in improving patients' quality of life. The evidence in the critical review by Fawzy et al.<sup>35</sup> targets cancer patients. The latter research group conducted a broad, but non-systematic, search on psychosocial interventions, such as educational techniques, behavioral training, individual psychotherapy and group interventions, and concluded benefits with regard to outcome measures such as coping, affective state, quality of life, knowledge, compliance, physical status, recurrence, and survival. The patients benefited most from a combination of educational, behavioral, individual, and group-based elements of the various interventions.

However, research on the behavioral and mental confrontation of death is still limited, especially for those who

are already close to death due to a life-threatening condition or older age.<sup>4,6,10</sup> Therefore, the following research question was derived: What is known about the effects of confronting one's own end of life on aspects of psychological comfort in people aged 80 and over and those with a life-threatening disease?

## Methods

A systematic review and meta-summary of findings according to Sandelowski and Barroso<sup>36</sup> was conducted. The study protocol was prospectively registered at PROSPERO international prospective register of systematic reviews (link: [https://www.crd.york.ac.uk/prospero/display\\_record.php?RecordID=153090](https://www.crd.york.ac.uk/prospero/display_record.php?RecordID=153090)). Reporting in this paper is based on the PRISMA guidelines (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) and the ENTREQ statement (Enhancing transparency in reporting the synthesis of qualitative research).<sup>37,38</sup>

### Search strategy

Three electronic bibliographic databases representing medical and psychological perspectives were searched systematically: Medline via PubMed, Web of Science Core Collection, and PsycINFO. Database searches were conducted from inception to October 2019 and completed by a forward and backward citation search of the included studies using Web of Science and a keyword search in Google Scholar. The search was updated in December 2020.

The search strategy was developed according to the PICO framework, including the following key concepts: Population: "old age" or "life-threatened", interest: "confronting", context: "end of life". Subject headings and free-text terms were identified and validated by co-authors, a librarian and experts of this research field. After conducting a preliminary set of scoping searches to test the search term, it was validated by checking whether retrieved key papers could be identified with the final search strategy in the three databases.<sup>39</sup> The search terms are provided in Appendix A. Retrieved studies were imported into a citation management software (EndNote X9, Clarivate Analytics, Boston) and duplicates were removed.

### Selection criteria

Full research reports (1975–2020) in English or German involving qualitative, quantitative, and mixed-methods studies were included to provide a comprehensive overview of all available research literature. Two different target groups were selected: Older individuals ( $\geq 65$  years) and patients with a life-threatening disease (disease that

may or may not shorten a person's life without specification, e.g. motor neuron disease) or life-limiting disease (a disease without curative treatment option, e.g. advanced cancer).<sup>40</sup> Studies were deemed eligible if the patients' perspective on confronting death, dying, or one's own finitude was the main focus. Comments, abstracts, conference presentations, and other types of publication were excluded, as were studies that provided "second-order" perspectives (families or staff reporting on behalf of the target group). The search and selection criteria are summarized in Table 1.

### Review process

Two reviewers (HK, AH) screened titles and abstracts of 7288 retrieved research reports independently after piloting a sample of 100 abstracts to unify the rules of selection and decrease the likelihood of disagreement. An initial agreement of 90% was reached. Once all the abstracts had been screened, disagreements between the two reviewers regarding inclusion were discussed and inclusion criteria were specified where necessary. A third reviewer (JS) was consulted for agreement to resolve discrepancies. This stage resulted in the inclusion of 151 research reports whose full texts were screened against eligibility criteria.

### Data extraction

The primary focus was on the results and discussion sections of the included studies. Study data were extracted using a pretested data extraction sheet. Two authors (HK, AH) conducted a final check on the data extraction to ensure consistency.

### Quality appraisal

The quality of the included studies was assessed independently by HK and AH using tools from the Critical Appraisal Skills Programme (CASP) for qualitative and quantitative research, as well as for reviews and meta-analyses.<sup>41</sup> Additionally, the mixed-methods appraisal tool (MMAT) was applied for mixed-methods designs.<sup>42</sup> The checklists cover three main areas: validity, trustworthiness of results, and value and relevance. Quality appraisal was conducted not to weight study findings, but rather to ensure transparency and discuss the robustness of the data.

### Data synthesis

Quantitative and qualitative data were combined into a meta-summary using an integrated approach. First, the quantitative findings were converted into textual descriptions in order to enable integration with the



**Table 1.** Search and selection criteria.

Criterion	Inclusion	Exclusion
Population	Participants aged 65 or older (mean age or median age of study population is 65 or older) OR Participants with a life-threatening or life-limiting disease according to the study report Mixed participant groups: inclusion, if results for target group can be separated	Mean age or median age is below 65 for participants without life-threatening diseases Mixed participant groups: exclusion, if results are mixed and cannot be separated Studies providing second-order perspective (families or staff reporting on behalf of the target group)
Phenomenon of interest	Studies on patients' accounts of confronting finitude Studies on effects of confronting finitude as an outcome	Studies not focusing on confronting finitude Indirect approaches of confronting finitude: for example, hypnosis, arts Studies not focusing on effects after confronting finitude but reporting on status-quo
Study design	Qualitative studies, quantitative studies, mixed-methods studies, reviews	Studies with insufficient methodological quality
Language	English, German	Other languages
Type of research report	Full research reports from 1975 onwards	Poster abstracts, editorials, comments, study protocols

qualitative data.<sup>43</sup> Consecutively, an aggregation and synthesis was conducted based on the qualitative meta-summary technique by Sandelowski and Barroso.<sup>36</sup> Qualitative meta-summary is a quantitatively orientated aggregation approach, and includes the extraction, separation, editing, grouping, and abstraction of text findings into numbers and textual descriptions.<sup>44</sup> Extracted study findings were analyzed using MAXQDA Analytics Pro 2020 (Verbi software, Berlin). Two authors (HK, AH) defined coding categories based on data within a test sample of three studies. Results were discussed until a basic inductive coding system focusing on outcome categories was reached. Following this, the first author continued to code studies' findings. The results were validated by the second author and refined during discussion. Subsequently, studies' findings were abstracted to statements representing the effect of confronting one's own finitude on the respective outcome. Finally, all statements were summarized by outcome category to provide an overall evaluation.

In order to avoid double reporting, findings from primary studies that had already been processed in the findings of the included reviews were only included when summarizing the outcomes in cases where they provided additional information.

## Results

### *Characteristics of the included studies*

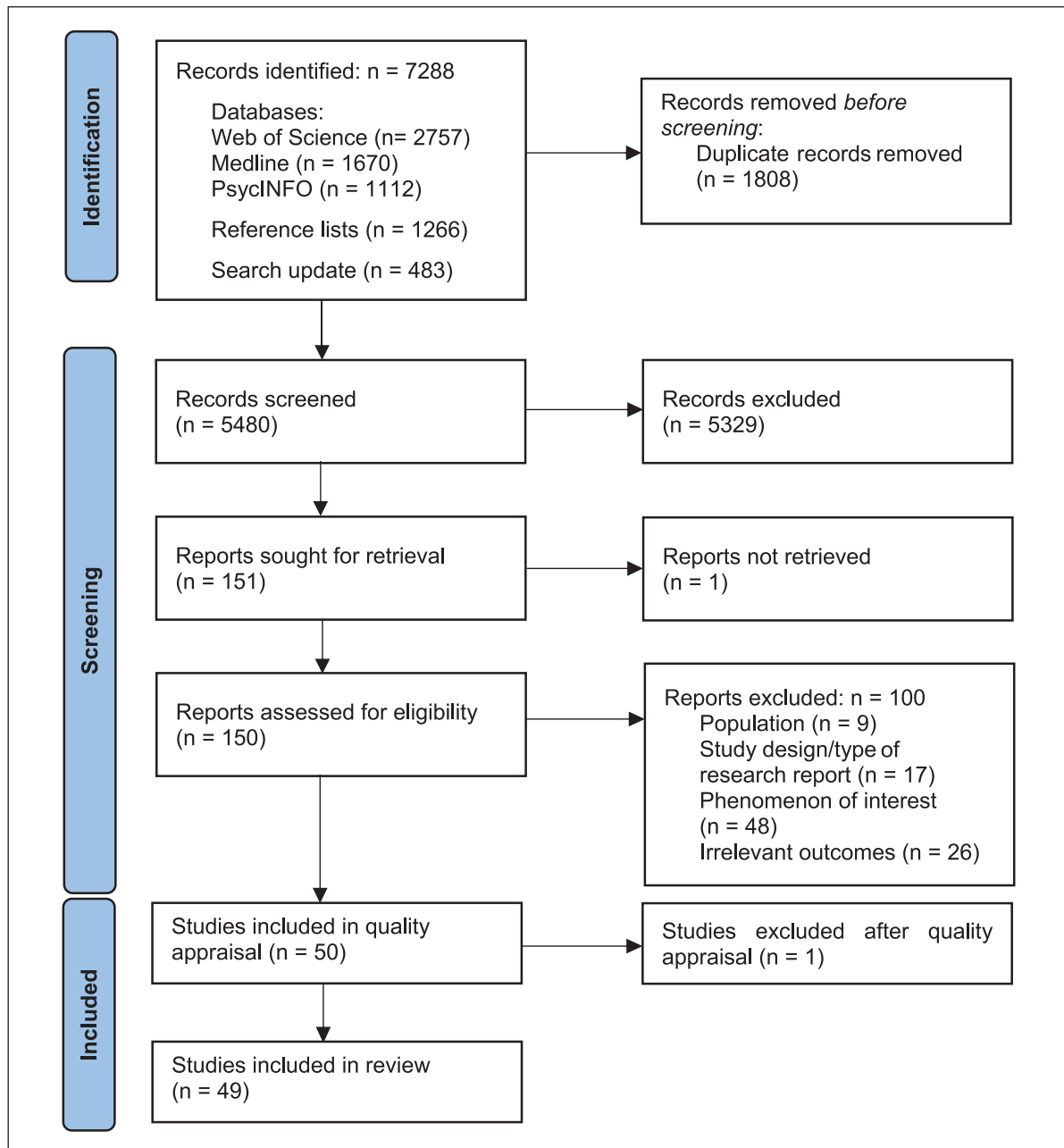
A total of 49 studies met the eligibility criteria and were included in this review (Figure 1). Eleven reviews or meta-analyses and 38 primary studies were identified, the latter including 6 qualitative studies, 29 quantitative studies, and 3 studies with a mixed-methods design. Of the 32

studies that analyzed quantitative data, 13 single-arm, 12 two-arm, and 7 three-arm trials were included, 17 of which were categorized as randomized controlled trials; all but one study included a baseline measurement. The points and intervals of measurement varied substantially: The results of 17 studies were based on a pretest-posttest design, eleven were based on a pretest-posttest design with at least one follow-up, three studies included a baseline and two or more follow-ups, and one was based on a cross-sectional design. The posttest measure typically occurred within 2 months after intervention, and ranged from 4 days to 1 year. Most of the studies were published between 2010 and 2020 and conducted in the USA ( $n = 16$ ) or China ( $n = 9$ ). An overview of the studies' characteristics is provided in Table 2, and summarized results of included studies are presented in Table 3.

All but one study was found to be of sufficient or good quality. The results of the quality appraisal were summarized by domain for the quantitative and qualitative primary studies and reviews (Appendix B) and for mixed-methods studies (Appendix C). The article by Waldrop<sup>86</sup> was excluded due to deficient methodological quality.

### *Approaches of confronting finitude*

The different approaches of actively confronting one's own finitude were grouped into four categories: (1) psychosocial interventions, using a narrative therapeutic approach focusing on reflection on the life one has lived, (2) meaning-enhancing interventions, using counseling-based intervention focusing on strengthening the patient's sense of meaning, purpose, and dignity, (3) educational courses, focusing on the transmission of knowledge, and (4) experiential learning, defined as personal experiences and actions regarding end-of-life care.



**Figure 1.** Identification and selection of studies based on the PRISMA statement.<sup>38</sup>

*Psychosocial interventions.* The majority of the included studies ( $n = 35$ ) included the evaluation of psychosocial interventions with the aim of alleviating distress,<sup>65</sup> reducing self-reported suffering (including depression and anxiety), and increasing quality of life and well-being.<sup>76</sup> All forms of life review interventions, dignity therapy, and the outlook interventions were allocated to this category, and aimed predominantly at patients with life-threatening circumstances. The main focus of these interventions is on reviewing and re-evaluating the patient's life, relationships, and related feelings. Some interventions included creating an individual legacy product (e.g. a booklet). The

intervention time ranged from three to eight sessions, lasting 30–60 min.

*Meaning-enhancing interventions.* Eight studies were classified as meaning-enhancing interventions aimed at sustaining or enhancing the patient's sense of meaning and purpose and alleviating psychosocial distress.<sup>87</sup> In psychotherapeutic individual or group-session-based settings, participants are encouraged to reflect on identity, legacy, hope, and the finitude of life. The following interventions were included: CALM (Managing Cancer and Living Meaningfully), Soul's Legacy program, Individual

Table 2. Study characteristics.

First author, country	Study design	Sample (number of participants: inclusion/ completion)	Main objectives	Approach of confronting finitude	Data collection
Aday and Shahan, <sup>45</sup> USA	Quantitative: one-group pretest-posttest design	41 nursing home residents (mean age: 78) with psychological abnormalities	Impact of a death education program for institutionalized elderly	Educational course: seven group sessions (45–60 min)	Templer's death anxiety scale (DAS), Geriatric Depression Scale (GDS), Life Satisfaction Index A (LSI-A)
Ando et al., <sup>46</sup> Japan	Quantitative: two-armed randomized controlled trial, pretest-posttest design	77/68 terminally ill cancer patients (mean age: 64.5)	1. Efficacy of the short-term life review to enhance the sense of meaning in terminally ill cancer patients 2. Effects of the short-term life review on anxiety, depression, and on elements of a good death	Psychosocial intervention: short-term life review, two sessions	Functional Assessment of Chronic Illness Therapy-Spiritual Well-Being (FACIT-Sp-12), Hospital Anxiety and Depression Scale (HADS), numeric scale for psychological suffering, items from the Good Death Inventory (hope, burden, life completion, preparation)
Ando et al., <sup>47</sup> Japan	Quantitative: one-group pretest-posttest design	35/30 terminally ill cancer patients (mean age: 74)	Efficacy of the short-term life review on the spiritual well-being, anxiety, depression, suffering and happiness	Psychosocial intervention: short-term life review, two sessions	Japanese version of Functional Assessment Chronic Illness Therapy-Spiritual well-being (FACIT-Sp-12), Japanese version of the Hospital Anxiety and Depression Scale (HADS), numeric rating scale for suffering and happiness
Aoun et al., <sup>48</sup> Australia	Quantitative: one-group pretest-posttest design	35/27 patients with motor neuron disease (mean age: 64.3)	Acceptability, feasibility, and effectiveness of dignity therapy	Psychosocial intervention: dignity therapy, three sessions	Acceptability: ratings of participants' views on whether the intervention has helped them, feasibility: number of visits by therapist, number of days to complete the therapy, time taken by therapist to deliver the therapy, Patient Dignity Inventory (PDI), Amyotrophic Lateral Sclerosis Assessment Questionnaire-5 (ALSAQ-5), Functional Assessment of Chronic Illness Therapy—Spiritual Well-Being (FACIT-Sp 12), Herth Hope Index (HHI)
Bentley et al., <sup>26</sup> Australia	Narrative mixed-methods review	39 publications (33 articles, 1 systematic review, 5 letters to the editor)	Synthesize and summarize qualitative and quantitative evidence on the efficacy of dignity therapy	Psychosocial intervention: dignity therapy	Reviewed outcome measures: efficacy, feasibility and potential effectiveness with different study populations
Breibart et al., <sup>49</sup> USA	Quantitative: two-armed randomized controlled trial, pretest-posttest design and follow-up	90 patients with advanced solid tumor cancers (mean age: 60.1)	Impact of meaning-centered group psychotherapy on spiritual well-being, meaning and psychological distress	Meaning-enhancing intervention: meaning-centered group psychotherapy, four sessions	Functional Assessment of Chronic Illness Therapy—Spiritual Well-Being (FACIT-Sp-12), Beck Hopelessness Scale (BHS), Schedule of Attitudes toward Hastened Death (SAHD), Life Orientation Test (LOT), Hospital Anxiety and Depression Scale (HADS)
Breibart et al., <sup>50</sup> USA	Quantitative: three-armed randomized controlled trial, pretest-posttest design and follow-up	120/67 patients with stage II or IV cancer (mean age: 54.4)	Effects of individual meaning-centered psychotherapy (spiritual well-being, meaning, quality of life, hopelessness)	Meaning-enhancing intervention: individual meaning-centered therapy, seven sessions (60 min)	Functional Assessment of Chronic Illness Therapy—Spiritual Well-Being (FACIT-Sp 12), McGill Quality of Life Questionnaire (MQLQ), Hospital Anxiety and Depression Scale (HADS), Beck Hopelessness Scale (BHS), Memorial Symptom Assessment Scale (MSAS): symptom burden (MSAS-Sx), symptom distress (MSAS-DI)
Brozek et al., <sup>51</sup> Poland	Mixed-methods design: one-group cross-sectional analysis of statements	11/10 patients with severe COPD (mean age: 73)	Assess overall feasibility and potential benefits of Dignity Therapy	Psychosocial intervention: dignity Therapy, four sessions (30–60 min)	Qualitative analysis of narrative interviews, Hospital Anxiety and Depression Scale (HADS), Edmonton Symptom Assessment System (ESAS), Spiritual Needs Questionnaire (SpNQ), Likert scale for satisfaction
Chen et al., <sup>27</sup> China	Systematic review and meta-analysis	9 randomized controlled trials and 2 controlled clinical trials, participants with a confirmed life-threatening diagnosis, 575 patients (mean age: 56.34)	Effects of Life Review on psycho-spiritual well-being in patients (evaluating psycho-spiritual outcomes, e.g. depression, anxiety, life satisfaction, self-esteem, quality of life)	Psychosocial intervention: life review, 2–6 sessions (30–120 min)	Reviewed outcome measures: depression, quality of life, purpose in life, anxiety, hope, optimism, additional outcomes

(Continued)

Table 2. (Continued)

First author, country	Study design	Sample (number of participants: inclusion/ completion)	Main objectives	Approach of confronting finitude	Data collection
Chochinov et al., <sup>52</sup> Canada	Quantitative: one-group pretest-posttest design	129/100 terminally ill cancer patients (mean age: 63.9)	Feasibility of dignity therapy and its impact on measures of psychosocial and existential distress	Psychosocial intervention: dignity therapy (30–60 min)	Seven-point ordinal scale for: depression, dignity, anxiety, suffering, hopefulness, desire for death, suicide, and sense of well-being, a two-item quality-of-life instrument, revised Edmonton Symptom Assessment Scale (ESAS)
Chochinov et al., <sup>53</sup> Canada	Quantitative: three-armed randomized controlled trial, pretest-posttest design	441/326 terminally ill cancer patients (mean age: intervention: 64.2, controls: 66.7 and 64.3)	Effects of dignity therapy in terms of reducing psychological, existential, and spiritual distress	Psychosocial intervention: dignity therapy (about 60 min)	Palliative Performance Scale, subscales meaning, peace and faith of Spiritual Well-Being Scale (FACT-Sp-12), Patient Dignity Inventory (PDI), Hospital Anxiety and Depression Scale (HADS), survey: experiences, two-item Quality of Life Scale, modified Edmonton Symptom Assessment Scale (ESAS)
Dose et al., <sup>54</sup> USA	Quantitative: one-group pretest-posttest design and follow-up	20/18 patients with advanced pancreatic or lung cancer (mean age: 63.2 and 64.0)	Influence of the combination of dignity therapy and life plan on psychosocial outcomes	Psychosocial intervention: dignity therapy in combination with a life plan, three sessions	Distress thermometer, Patient Dignity Inventory (PDI), Functional Assessment of Cancer Therapy-Hepatobiliary (FACT-Hep), Functional Assessment of Cancer Therapy-Lung (FACT-L), Linear Analog Self-Assessment for quality of life, Functional Assessment of Chronic Illness Therapy—Spiritual Well-Being (FACT-Sp-12)
Erlen et al., <sup>55</sup> USA	Quantitative: two-armed randomized controlled trial, pretest-posttest design and two follow-ups	20 patients with acquired immune deficiency syndrome (mean age: intervention group: 43.7, control: 40.4)	Effectiveness of using life review on depressive symptoms, purpose in life, self-esteem, and quality of life	Psychosocial intervention: life review therapy, four sessions (60–120 min)	HIV dementia Scale (HDS), Center for Epidemiological Studies Depression Scale (CES-D), Purpose in Life Test (PLL), Rosenberg's Self-esteem Scale (RSES), Ferrans and Powers Quality of Life Index (QLI)
Fitchett et al., <sup>56</sup> USA	Mixed-methods systematic review	25 articles representing 12 quantitative (8 controlled clinical trials and 4 randomized controlled trials) and 3 qualitative studies with terminally ill participants or older adults living in long-term care	Synthesis of findings from existing Dignity Therapy studies regarding feasibility, acceptability and effects	Psychosocial intervention: dignity therapy	Reviewed outcome measures: depression, anxiety, symptoms, quality of life, hope, spiritual well-being, dignity, function, acceptability, feasibility and effectiveness
Grewe, <sup>57</sup> USA	Qualitative: in-depth approach of case study analysis	34 older adults (mean age: 71.3)	Evaluation of a program to help senior adults to cope inevitable existential concerns and the effects on alleviating existential distress	Psychosocial intervention: Souls Legacy Program, five sessions	In-depth analysis of case studies
Guerrero-Torrelles et al., <sup>29</sup> Spain	Mixed-methods systematic review	12 articles included, 359 patients with advanced stages of disease	Description of contextual factors, procedures and outcomes of meaning-in-life-interventions and examination of the mechanisms	Meaning-enhancing intervention: 9 different interventions, 2–8 sessions (30–90 min)	Reviewed outcomes: meaning in life, subjective outcomes reported by patients, clinical benefits
Haight, <sup>58</sup> USA	Quantitative: three-group pretest-posttest design	60/51 completed older adults (mean ages in groups: 73–79)	Effects of structured process of life review on well-being (satisfaction, psychological well-being, depression, activities of daily living)	Psychosocial intervention: life review process, six sessions	Life Satisfaction Index A (LSIA), Affect-Balance Scale (ABS), Zung's Self-Rating Depression Scale (SDS), OARS (Older Americans Resources and Services)
Hall et al., <sup>59</sup> UK	Quantitative: two-armed randomized controlled trial, pretest-posttest design and follow-up	45 patients with advanced cancer (mean age: intervention: 64.9, control: 65.3)	Acceptability and potential effectiveness of dignity therapy to reduce distress	Psychosocial intervention: dignity therapy, 2–8 sessions	Dignity related distress (PDI), Herth Hope Index, Hospital Anxiety and Depression Scale (HADS), EQ-5D, two-item measure of quality of life, 10-point Likert scale for quality of life and satisfaction, self-reported benefits
Hall et al., <sup>60</sup> UK	Quantitative: two-armed randomized controlled trial, pretest-posttest design and follow-up	60 participants living in nursing homes (mean age: intervention: 84.4, control: 81.4)	Feasibility, acceptability and potential effectiveness of dignity therapy to reduce psychological and spiritual distress	Psychosocial intervention: dignity therapy, two sessions	Geriatric Depression Scale, Herth Hope Index, EQ-5D, Patient Dignity Inventory (PDI), two-item measure for quality of life, rating of participants for acceptability, documentation of outlay for feasibility

(Continued)

Table 2. (Continued)

First author, country	Study design	Sample (number of participants: inclusion/ completion)	Main objectives	Approach of confronting finitude	Data collection
Houmann et al., <sup>61</sup> Denmark	Quantitative: one-group pretest-posttest design and follow-up	80/31 patients with incurable cancer (mean age: 63)	Assess and explore the interest in and the evaluation and effectiveness of dignity therapy	Psychosocial intervention: dignity therapy, two sessions	Six items from the Structured Interview for Symptoms and Concerns (SISC), Patient Dignity Inventory (PDI), Quality of Life Questionnaire Core 15 Palliative Care (EORTC QLQ-C15-PAL), Hospital Anxiety and Depression Scale (HADS), Palliative Performance Scale—version 2 (PPSV2), Nine items of the Dignity Therapy Patient Feedback Questionnaire
Iani et al., <sup>62</sup> Italy	Quantitative: two-armed randomized controlled trial, pretest-posttest design and follow-up	64/35 terminally ill patients (mean age: 75.1)	Effects of Dignity therapy on specific dimensions of spiritual well-being, demoralization and dignity-related distress	Psychosocial intervention: Dignity Therapy, three sessions	Functional Assessment of Chronic Illness Therapy-Spiritual Well-Being Scale (FACT-Sp-12), Demoralization Scale-II (DS-II), Patient Dignity Inventory (PDI)
Julião et al., <sup>63</sup> Portugal	Quantitative: two-armed randomized controlled trial, pretest-posttest design	92/80 terminally ill patients (mean age: 66.1)	Influence of dignity therapy on demoralization syndrome, the desire for death, and a sense of dignity in terminally ill inpatients	Psychosocial intervention: dignity therapy, three sessions	Desire for death rating scale (DDRS), Patient Dignity Inventory (PDI)
Julião et al., <sup>64</sup> Portugal	Quantitative: two-armed randomized controlled trial, pretest-posttest design and two follow-ups	92/80 terminally ill patients (mean age: 66.1)	Efficacy data for dignity therapy on symptoms of depression and anxiety	Psychosocial intervention: dignity therapy, three sessions (30–60 min)	Hospital Anxiety and Depression Scale (HADS)
Kwan et al., <sup>65</sup> China	Mixed-methods design: two-armed randomized controlled trial, pretest-posttest design and qualitative analysis of interviews	109/89 patients with a life-limiting disease (mean age: 64.4)	Effectiveness of short-term life review intervention and its implementation in palliative care settings: effectiveness, anxiety, depression, delivery of intervention, participation, acceptance	Psychosocial intervention: short-term life review, two sessions (approximately 45 min)	McQill Quality of Life Index-Hong Kong version (MQOL-HK), Hospital Anxiety and Depression Scale (HADS), qualitative content analysis of semi-structured interviews
Kwan et al., <sup>66</sup> China	Mixed-methods systematic review	7 studies (5 quantitative studies and 2 qualitative studies), 222 patients with a life-limiting or life-threatening disease	Effectiveness of life review in enhancing the spiritual well-being	Psychosocial intervention: three groups of life review interventions: Structured Life Review (SLR) program, four sessions, Short Term Life Review (STLR), two sessions, Outlook program, three sessions	Reviewed outcome measures: anxiety, depression, spiritual well-being
Lan et al., <sup>28</sup> China	Systematic review and meta-analysis	15 studies (11 randomized controlled trials and 4 controlled clinical trials) with 863 older adults (aged 60 or older)	Effects of life review on psychosocial outcome variables, such as depression, life satisfaction, hopelessness and quality of life	Psychosocial intervention: any forms of life review interventions (2–12 sessions)	Reviewed outcome measures: quality of life, depression, life satisfaction, ego-integrity, hopelessness, self-esteem, memory, and well-being
Lee et al., <sup>67</sup> Canada	Mixed-methods design: one-group pretest-posttest design and qualitative analysis of interviews	21/18 patients with breast or colorectal cancer at different phases (mean age: 57)	Develop an intervention that uniquely addresses the existential impact of cancer through meaning-making coping strategies and explore the interventions' impact on psychological adjustment	Meaning-enhancing intervention: meaning-making intervention, eight sessions	Content analysis of interviews, Hospitality anxiety and depression scale (HADS), Impact of Event Scale, Karnofsky Performance Status Scale, Life Experience Survey, Life Orientation Test-Revides (LOT-R), Psychological Adjustment to Illness Scale Self-Report, Purpose in Life Scale, Rosenberg Self-Esteem, Social-Support Questionnaire-Short-Form, Symptom Distress Scale
Li et al., <sup>68</sup> China	Systematic review and meta-analysis	10 randomized controlled trials, 904 patients with advanced cancer	Effect of the dignity therapy on anxiety, depression, dignity-related distress, and quality of life	Psychosocial intervention: dignity therapy	Reviewed outcome measures: distress, anxiety, depression, quality of life

(Continued)

Table 2. (Continued)

First author, country	Study design	Sample (number of participants: inclusion/ completion)	Main objectives	Approach of confronting finitude	Data collection
Lo et al., <sup>69</sup> Canada	Quantitative: one-group, baseline and two follow-ups	50/16 patients with advanced or metastatic cancer (mean age: 52)	Feasibility and preliminary effectiveness of CALM to reduce emotional distress and promote psychological well-being and growth	Meaning-enhancing intervention: CALM (Managing Cancer and Living meaningfully), 3–8 sessions (60 min)	Patient Health Questionnaire-9 (PHQ-9), Functional Assessment of Chronic Illness Therapy—Spiritual Well-Being (FACT-Sp-12), Death and Dying distress Scale (DADDS), Modified Experiences in close Relationships (ECR-M16), Post-Traumatic Growth Inventory (PTGI)
Martinez et al., <sup>70</sup> Spain	Mixed-methods systematic review	28 studies in patients with advanced life-threatening diseases	Analyze the outcomes of dignity therapy	Psychosocial intervention: dignity therapy	Reviewed outcome measures: effectiveness (depression, suffering, anxiety, will to live, quality of life, survival, meaning, and purpose in life, hopefulness, benefits, well-being, dignity-related distress, dignity, burden, acceptability, feasibility) Pretest and posttest questionnaires (preferences and attitudes toward advance directives)
Matsui, <sup>30</sup> Japan	Quantitative: two-armed pretest-posttest design and follow-up	121/112 older adults (mean age: intervention: 75.8, controls: 73.1)	Effectiveness of an educational intervention regarding end of life discussion, attitudes to and acceptance of this intervention	Educational course: 90-min educational program (video, lecture, handout, and discussion)	Content analysis of semi-structured interviews
Missim et al., <sup>71</sup> Canada	Qualitative: analysis of interviews	26 patients with advanced cancer (10 participated in the qualitative interview) (mean age: 59)	Subjective experience of advanced cancer patients receiving an individual psychotherapy: Managing Cancer and Living meaningfully (CALM)	Meaning-enhancing intervention: Managing Cancer and Living meaningfully (CALM), 3–6 sessions (45–60 min)	Content analysis of semi-structured interviews
Pautex et al., <sup>32</sup> Switzerland	Quantitative: one-group pretest-posttest design and follow-up	53 hospitalized patients with advanced cancer (mean age: 71)	Effect of advance directives completion on the satisfaction level with end-of-life care from both patients and their relatives and patients' motivations for deciding to formulate advance directives	Educational course: information about advance directives (written support, oral information, writing assistance)	Functional Independence Measure (FIM), Hospital Anxiety and Depression Scale (HADS), Edmonton Symptom Assessment System (ESAS), satisfaction (three questions adapted from "the satisfaction statement after death interview support PHASE II"), motivation to complete their advance directives and main cited items were collected
Rosenfeld et al., <sup>72</sup> USA	Quantitative: one-group pretest-posttest design	12/8 terminally ill cancer patients (mean age: 66.9)	Evidence for the feasibility, acceptability, and utility of an abbreviated version of Meaning-centered psychotherapy	Meaning-enhancing intervention: meaning-centered psychotherapy, three sessions (approximately 45 min)	Socio-demos graphic questionnaire, Distress Thermometer, Hospital Anxiety and Depression Scale (HADS), brief questionnaire eliciting their perceptions of the intervention and its utility, post-treatment questionnaire
Scarton et al., <sup>73</sup> USA	Quantitative: reanalysis of three-armed randomized controlled trial, pretest-posttest design	326 hospice/palliative care patients (mean age: 65.1)	Examination properties of a new measure of dignity impact (validity, reliability, and responsiveness to the intervention)	Psychosocial intervention: dignity therapy (about 60 min)	Dignity Impact Scale Items (DIS), derived from the Dignity Therapy Patient Feedback Questionnaire
Song et al., <sup>74</sup> USA	Quantitative: two-armed randomized controlled trial, pretest-posttest and follow-up design	58/56 (dyads) with end-stage renal disease (mean age: intervention 58.3, controls: 57.6)	Feasibility and acceptability of the Sharing Patients' Illness Representations to Increase Trust (SPIRIT) and effects on participants' psychosocial-spiritual well-being	Educational course: Sharing Patients' Illness Representations to Increase Trust (SPIRIT), one session (mean: 76 min)	Patient-Clinician Interaction Index, Quality of Patient-Clinician (or interventionist) Communication about End-of-Life Care, Goals of Care document Decisional Conflict Scale, Decision-Making Confidence Scale, Self-Perception and Relationship Tool (S-PRT), Dialysis Symptom Index, Short form 12 items health survey (version 2: SF12v2)
Sopchek, <sup>75</sup> USA	Qualitative: analysis of interviews	15 older adults (mean age: 84.5)	Examine prospective views about end-of-life in a study that explored their challenge of losing a loved one and study a sensitive topic such as an individuals' end of life and burden to older-aged participants	Experiential learning: experiencing death of a loved one	Content analysis of interviews

(Continued)

Table 2. (Continued)

First author, country	Study design	Sample (number of participants: inclusion/completion)	Main objectives	Approach of confronting finitude	Data collection
Steinhauser et al., <sup>76</sup> USA	Quantitative: three-armed randomized controlled trial, baseline and two follow-ups	221/185 veterans with advanced cancer (mean age: 67.8)	Efficacy of outlook intervention (quality of life, preparation and completion, spiritual well-being, anxiety)	Psychosocial intervention: outlook intervention, three sessions (approximately 45 min)	Preparation and life completion subscales from the QJAL-E, five items from the tension/anxiety subscale from the modified Brief Profile of Mood States, Center for Epidemiological Studies—Depression scale, Functional Assessment of Cancer Therapy—General (FACT-G), Functional Assessment of Chronic Illness Therapy—Spiritual Well-Being (FACT-Sp-12)
Steinhauser et al., <sup>77</sup> USA	Quantitative: three-armed randomized controlled trial, pretest-posttest design	82/42 patients with a life-limiting disease	Impact of Outlook intervention on physical functioning, emotional function (anxiety and depression) and quality of life at the end of life	Psychosocial intervention: Outlook intervention, three sessions (45–60 min)	Memorial Symptom Assessment Scale, Rosow-Breslau ADL scale, Profile of Mood States sub-scale, Center for Epidemiologic Study of Depression (CESD short version), quality of end of life instrument (QUAL-E), Daily Spiritual Experience Scale
Teo et al., <sup>34</sup> Singapore	Systematic review	68 randomized controlled trials, patients with cancer or advanced cancer	Summarize the current and growing body of research in psychosocial interventions for advanced cancer patients	Psychosocial and Meaning-enhancing interventions and educational courses: cognitive behavioral therapy, Dignity Therapy, Life Review, narrative interventions, counseling, education-only, others	Reviewed outcome measures: intervention effectiveness (quality of life, well-being, anxiety, hope, depression, physical outcomes, satisfaction, generativity, distress, sense of dignity, sense of meaning, acceptability, feasibility)
Thronické et al., <sup>78</sup> Germany	Quantitative: one-group, baseline and two follow-ups	239 women (95 completed) with non-metastasized breast cancer (intervention group: n=73, control group: 66)	Exploring the impact of standard care plus Elaborate consultations and Life Review (ECLR) on patient-reported outcome measures	Psychosocial intervention: elaborate consultations and life review, 1–4 sessions (30–60 min)	Quality of Life Questionnaire (EORTC QLQ-C30)
van Gorp et al., <sup>79</sup> Netherlands	Qualitative: analysis of interviews	12 older persons with incurable cancer ( $\geq 70$ years of age)	Outlooks on life, including the values that are central to these outlooks of Dutch older adults living with incurable cancer	Experiential learning: preparation of end of life	Grounded theory-based analysis of semi-structured interviews
Vergo et al., <sup>80</sup> USA	Quantitative: one-group pretest-posttest design and follow-up	15/9 patients with metastatic stage IV colorectal cancer (median age: 56)	Effect of dignity therapy on death acceptance, distress, symptoms, quality of life, peacefulness, and scenario-based treatment choices	Psychosocial intervention: Dignity Therapy, two sessions	Success rate of enrollment, Likert-Scale for satisfaction, and peace, terminally illness acknowledgment (TIA), Distress Thermometer, Edmonton Symptom Assessment System (ESAS), 2-item quality of life scale, Hypothetical Advanced Care Planning Scenario (H-CAP-5)
Vig and Pearlman, <sup>33</sup> USA	Qualitative: analysis of interviews	26 terminally ill men with cancer or heart disease (mean age: 70.8)	Explore and understand what contributes to their quality of life while living with a terminal illness	Experiential learning: preparations for end of life	Grounded theory-based analysis of in-depth semi-structured interviews
Vuksanovic et al., <sup>81</sup> Australia	Quantitative: three-armed randomized controlled trial, pretest-posttest design	70/56 with advanced terminal disease (mean age: 57.7)	Evaluate the legacy creation component of dignity therapy by comparing this intervention with life review and waitlist control groups	Psychosocial intervention: dignity therapy and life review (mean: 54–61 min)	Brief measure of generativity and ego-integrity, Patient Dignity Inventory (PDI), The Functional Assessment of Cancer Therapy-General (FACT-G), Treatment Evaluation Form for impact on well-being
Wang et al., <sup>82</sup> China	Systematic review	7 randomized controlled trials, 955 participants with advanced cancer	Assess and synthesize the clinical evidence available from randomized controlled trials of the effects of therapeutic life review interventions on spiritual well-being, psychological distress, and quality of life among patients with terminal or advanced cancer	Psychosocial interventions: Life Review, 1–7 sessions	Reviewed outcome measures: spiritual well-being, psychological distress, quality of life

(Continued)

**Table 2. (Continued)**

First author, country	Study design	Sample (number of participants: inclusion/completion)	Main objectives	Approach of confronting finitude	Data collection
Xiao et al., <sup>83</sup> China	Qualitative: analysis of interviews	40/26 patients: with advanced cancer (mean age: 59.1)	Elicit patients' perceptions of their participation in a life review program for Chinese patients with advanced cancer	Psychosocial intervention: life review, three sessions (45–60 min)	Content analysis of semi-structured interviews
Xiao et al., <sup>84</sup> China	Quantitative: two-armed randomized controlled trial, pretest-posttest design and follow-up	80/56 patients with advanced cancer (mean age: intervention: 59.8, control: 58.5)	Examine effects of life review program on quality of life for patients with advanced cancer	Psychosocial intervention: life review, three sessions	Numeric item scale for quality of life, adopted Quality-of-Life Concerns in the End-of-Life Questionnaire
Zhang et al., <sup>85</sup> China	Systematic review	Nine randomized controlled trials and six controlled clinical trials, patients with cancer (mean age from 44.4 to 72.5)	Systematically identify and summarize the characteristics of studies related to life review on mental health and well-being among cancer patients	Psychosocial intervention: life review interventions, 2–6 sessions	Reviewed outcome measures: effects of life review (depression, anxiety), hope, self-esteem, quality of life

Meaning-Centered Therapy (IMCP), Meaning-Centered Psychotherapy, and Meaning-Making intervention. The number of sessions varied from three to eight, typically with a duration of 60 minutes.

*Educational courses.* Four education-based interventions were included in this category. These aimed to decrease anxiety and depression, empower informed decisions regarding end-of-life planning, and enhance communication within this process. Approaches focused on knowledge transfer within one to seven individual or group sessions, each lasting 45–90 min. Delivered in the form of lectures, videos, hand-outs or conversations, these interventions were used to discuss topics such as death preparation, advanced directives, fears, and experiences.

*Experiential learning.* Three studies were categorized as experiential learning. The participants were interviewed regarding their experiences of preparing for the end of their lives, the effects on quality of life, and the effect that losing a significant other had had on their attitudes to life and death.

### Effects of confronting finitude

*Attitude to life and death.* Measures of purpose and meaning, sense of dignity, will to live, and death acceptance were included in this category.

Seven reviews reported considerable improvements in sense of purpose and feeling meaningful, though these differed in significance.<sup>26,27,29,34,56,70</sup> Higher levels might be explained by factors such as legacy documents and reconsidering life and experiences.<sup>70</sup> However, conclusions for both sense of dignity and dignity-related distress remained inconsistent. There was little evidence for the alleviation of dignity-related distress and the heightening of the sense of dignity, but for desirable effects.<sup>26,27,66,70</sup> One review even found significant positive effects.<sup>68</sup> Furthermore, three included reviews evaluated changes concerning the desire to die and will to live, and that meaning-in-life interventions and dignity therapy had a positive impact in this regard.<sup>26,29,70</sup> There was less exploration into the effects on death acceptance, though one intervention did show improvements for this outcome.<sup>26</sup>

Seven out of the fourteen studies not already included in the reviews supplement these findings. Most of them presume a heightened sense of purpose and meaning<sup>51,57,65,71,72,83</sup> and increased levels for sense of dignity after confronting finitude.<sup>54,73</sup> Deviating results that indicated nonsignificant changes for the latter outcome measure were rare.<sup>62</sup> For dignity-related distress, both significant<sup>63</sup> and nonsignificant decreases were reported.<sup>62,73</sup>

One study confirmed the results of the reviews and concluded a decreased desire to die.<sup>63</sup> Participants also indicated



**Table 3.** Overview of analyzed studies per outcome category and synthesized evidence.

Outcomes	Primary studies (numbered references)	Secondary studies (numbered references)	Trend of synthesized evidence
Attitude to life and death	33,45,51,54,57,62,63,65,71–73,76,83	26,27,29,34,56,66,68,70	Enhanced for meaning in life, will to live and death acceptance, inconsistent effects for sense of dignity
Negative emotions	45,57,62–65,72,81,83	27–29,66,70,82	Decreased for hopelessness and suffering, inconsistent effects for sadness and stress
Depression and anxiety	32,45,58,65,69,76	26–29,34,56,66,68,70,85	Decrease in depression and anxiety
Positive emotions	45,49,51,52,57,58,62,65,67,71,72,75,76,79,81,83	26–28,70,85	Increased satisfaction, optimism, gratitude and hope
Quality of life and well-being	46–48,50,51,53–55,58–61,65,69,73,74,76,80,81,83	26–29,34,56,66,68,70,82,85	Enhanced well-being, inconsistent effects on quality of life
Physical outcomes	47,55,58,61,77,78,84	26–29,34,70	Advantages in survival time, improved cognitive functioning, inconclusive results on physical condition
Preparing end of life	30,46,61,71,76,81,83	26,27,29,66	Favorable effects on life completion and coping ability, enhanced sense of generativity and improvements in decision making and completing advance directives
Personal relation	30,51,57,58,65,69,71	34,70	Improvements in initiating discussions and feeling comfortable within communication
Self-concept	33,65,71,83	27–29,34,70,85	Improved self-esteem, self-efficacy and ego-integrity, inconclusive results on feeling burdensome

that being confronted with the end of life had given them the opportunity to move toward an acceptance of life.<sup>83</sup> They stated that organizing and preparing the last phase of life, including planning their funeral, would lead to a good death,<sup>33</sup> while very few refused to discuss this issue.<sup>45</sup> Three further studies concluded that there was a drop in avoidance behavior after being confronted with finitude, and that these patients demonstrated an increased acceptance of death and sickness.<sup>33,76,83</sup>

**Negative emotions.** Negative emotions were operationalized using measures of hopelessness, suffering, and feelings of sadness or stress.

The outcomes of the included reviews suggested that the effects on these symptoms and on general distress following the intervention were inconclusive. Martínez et al.<sup>70</sup> summarized the results of non-randomized studies and reported improvements regarding existential and psychosocial measures of distress. In other reviews, there was little to no evidence of a decrease in distress,<sup>27,66,82</sup> though scores on hopelessness decreased.<sup>28,29</sup>

One out of seven further primary studies not included in the aforementioned reviews showed improved suffering scores,<sup>81</sup> and another study confirmed a significant alleviation of negative emotions.<sup>62</sup> Encouraging patients to create individual generativity documents was found to be crucial in mitigating negative emotions such as helplessness.<sup>63,64</sup> While data on hopelessness in reported reviews indicated nonsignificant changes favoring improvements as a result of encouraging patients to be proactive and motivating them to create individual generativity documents, there

was a minority of participants who stated that interventions such as life review interventions, educational approaches, and meaning-centered interventions triggered negative emotions and distress or sadness.<sup>45,57,65,72,83</sup>

**Depression and anxiety.** The most commonly examined effects were anxiety and depression and all studies showed indications of improvement.

Ten reviews and meta-analyses indicated a significant or nonsignificant improvement in depression,<sup>26–29,34,56,66,68,70,85</sup> although some included primary studies with inconclusive evidence.<sup>26–29,34,56,66,68,70,85</sup> Comparable positive results from five reviews summarized positive but mainly nonsignificant effects on anxiety.<sup>26,27,66,68,85</sup>

Four primary studies indicated nonsignificant changes for anxiety but desirable effects and considerable improvements,<sup>32,45,58,65</sup> while one research group found significant decreases in anxiety over time.<sup>69</sup> Nevertheless, Steinhäuser et al.<sup>76</sup> found neither remarkable nor sustainable improvements for anxiety and depression measures.

**Positive emotions.** Positive emotions were defined as the experience of appreciated actions or experiences, and represented by measures of satisfaction, optimism, gratitude, and hope.

The findings of included reviews reported on benefits and optimism experienced following intervention.<sup>26,70</sup> There was compelling data indicating mostly nonsignificant changes, but high levels of hope for follow-up assessments.<sup>26–28,70</sup> However, one review provided incongruent results concerning hopefulness.<sup>85</sup>

Further primary studies found that satisfaction levels increased following life review therapy and dignity therapy, the two most frequently evaluated types of intervention.<sup>58,65,81,83</sup> The majority of reported effects on this outcome measure were based on qualitative data. However, there were two trials that indicated significant increases in scores for happiness<sup>45</sup> and significant superiority in matters of helpfulness.<sup>81</sup> The participants of four further studies perceived the different approaches as helpful, especially the opportunity to speak freely and the legacy document that formed part of some interventions.<sup>45,57,72,76</sup> In addition to this, some participants stated that life reflection had helped them to mentally organize their memories, thoughts and feelings.<sup>52</sup>

One quantitative study provided data on increased hope,<sup>51</sup> supplemented by qualitative data on increased perception of hope following preparation for the end of life and the organization of the associated documents.<sup>75</sup> The participants of four studies indicated that various approaches had brought them a sense of relief.<sup>71,76,83</sup> A small number of the studies evaluated aspects of positive emotions such as optimism,<sup>49,67</sup> gratitude, and feeling peaceful,<sup>57,65</sup> or at least stable sense-of-peace levels compared to the control group.<sup>62</sup> Qualitative data on sense of peace implied that arranging a legacy can have a positive impact.<sup>79</sup>

*Quality of life and well-being.* The dimensions of quality of life and well-being, which included spiritual and psychological well-being, were among the most frequently studied outcome measures.

Nine reviews evaluated elevated levels in the spiritual<sup>29,34,56,66,82</sup> and psychosocial dimensions of well-being.<sup>27,34</sup> Overall well-being was also found to increase following intervention.<sup>28,29,70,85</sup>

The majority of included reviews reported that the effects of interventions on quality of life were at least beneficial and resulted in significant changes.<sup>26–29,34,56,66,70,82,85</sup> By contrast, Li et al.<sup>68</sup> found that the effect of these interventions on overall quality of life was unclear.

Further results from primary studies on well-being following interventions demonstrated heterogeneity, albeit favoring improvements. Four studies showed significantly higher rates of well-being in the follow-up assessment,<sup>46,47,65,74</sup> and three studies reported significant differences compared to the control groups.<sup>50,53,58</sup> Favorable effects were found for psychosocial, spiritual, and social well-being.<sup>51,69,76,80,83</sup> However, two studies reported only stable quality of life scores or small, nonsignificant improvements.<sup>48,54</sup>

The supplementary data of primary studies did not show significant changes for dimensions of quality of life, although several participants stated that the approach was helpful, for instance with regard to feeling good when talking about oneself or feeling close to

loved ones.<sup>48,55,59,60,73,76,80,81</sup> Additionally, significant improvements were found with regard to overall quality of life following individual meaning-centered psychotherapy.<sup>50</sup> However, one study found a nonsignificant decrease in quality of life measures within the longitudinal assessment.<sup>61</sup>

*Physical outcomes.* Physical constitution is defined using measures such as physical condition, cognitive function, daily living activities, and survival.

Two reviews summarized findings on survival advantages and found that survival time was higher after dignity therapy.<sup>26,70</sup> By contrast, nonsignificant differences were also found between groups,<sup>34</sup> and it was concluded that interventions focusing on dignity are unlikely to address physical pain.<sup>26</sup> However, the findings of three reviews indicated that suffering, fatigue, breathlessness, and distress improved.<sup>26,29,34</sup> For cognitive dimensions, Lan et al.<sup>28</sup> found positive effects on memory function following the life review intervention.

These effects were supplemented by primary studies and indicated that symptoms such as pain and loss of appetite, burden, and general physical discomfort were significantly improved, while other outcome measures, such as fatigue and nausea, did not reach significance.<sup>61,84</sup> Furthermore, measures of self-reported suffering showed a significant alleviation.<sup>47</sup> One study found strong evidence of improvements for cognitive function.<sup>78</sup>

Life review therapy induced significantly elevated overall health,<sup>78</sup> as well as nonsignificant effects.<sup>55</sup> No improvements in functional status or daily living activities were shown after confronting one's own finitude.<sup>58,77</sup>

*Preparing for end of life.* Preparation was defined as mentally working through worries and regrets<sup>16</sup> and actively preparing for the end of one's life. Respective effects encompass attitudes toward advance directives, decision-making, coping mechanisms, generativity, and life completion.

The results of two reviews demonstrated homogeneity regarding improvements in preparedness and learning to cope with emotional reactions toward one's disease and the impending death.<sup>29,66</sup> Among other effects, the shift in treatment choices toward non-life-prolonging care showed a tendency to change,<sup>26</sup> and measures of an altered coping ability revealed both significant and nonsignificant changes.<sup>27</sup>

In total, seven primary studies complement these findings, reporting favorable effects such as an impact on attitudes toward advance directives and clarification of end-of-life decisions, or switching to non-life prolonging measures.<sup>30</sup>

Considerable improvements were noted in preparing for the future<sup>76</sup> and helped with unfinished business (life completion tasks) following psychosocial interventions.

These aspects were part of the life completion tasks, which were reported to increase.<sup>61,81</sup> The improvement in taking final opportunities to feel that one's life is complete were significantly greater than in the control group,<sup>46</sup> while one study did not confirm any changes.<sup>76</sup>

Intervention participants also described an improved ability to cope<sup>71</sup> and said that reflecting on their lives had enabled them to plan for the near future, for example, funeral arrangements and financial and family issues.<sup>83</sup> They also showed a significantly heightened sense of generativity, care, and concern for future generations compared to baseline measures.<sup>81</sup>

*Personal relations.* The effects on measures of interpersonal relations included initiating discussions, feeling appreciated and appreciating interactions, and improved communication and social functioning.<sup>78</sup> Reported findings on this outcome measure were mainly based on qualitative data.

Two reviews emphasized participants' perceived improvements in patient-centered communication with both physicians and the patients' families, which influenced their personal relationships.<sup>34,70</sup>

Additionally, five primary studies reported on participants who felt empowered to initiate and facilitate discussions with their physicians,<sup>30</sup> family and friends,<sup>30,71</sup> to treasure relationships,<sup>65</sup> and to resolve issues.<sup>30,69</sup> Giving and allowing an insight into one's personal attitudes and values as part of several life review interventions left patients with a positive feeling.<sup>65</sup> The participants appreciated the opportunity to communicate, and reported an improved understanding of their reactions to their social surroundings.<sup>71</sup> Some valued the opportunity to communicate via a lasting legacy or in the presence of the intervention's facilitator<sup>71</sup> rather than talking to relatives directly.<sup>51</sup>

The relationship and interaction with the facilitator was rated positively, as was the bonding among participants.<sup>51,57,58</sup>

*Self-concept.* Changes in self-concept dimensions were operationalized as feeling burdensome, self-efficacy, self-esteem and self-worth, and sense of ego-integrity, the core component of which involves "the internal representation of the past as acceptable or satisfactory."<sup>88</sup> (p. 296).

In terms of self-esteem, three reviews reported elevated levels compared to control groups<sup>85</sup> and significant differences favoring positive effects after confronting finitude.<sup>27</sup> However, one meta-analysis<sup>28</sup> did not find a significant improvement in self-esteem.

Two reviews reported data on self-efficacy and found desirable effects.<sup>29,34</sup> The participants were able to re-establish a greater sense of connectedness to themselves and their significant others<sup>29</sup> and described a heightened sense of ego-integrity.<sup>34</sup>

It was revealed that the participants felt less burdensome.<sup>70</sup> Due to a lack of sufficient evidence, it might not be possible to draw conclusions regarding the effects of the interventions on whether patients felt like a burden.<sup>27</sup>

Further studies not already included in reviews supplemented the above findings, and their participants noticed that they had started to "feel good about [themselves]"<sup>65</sup> (p. 140) while three studies assessed the effect of feeling burdensome and therefore demonstrated heterogeneity. The participants believed that preparing for the last phase of their lives would minimize the burden on their loved ones after their deaths<sup>33</sup> and act as an enabler of strengthening the self-perception without increasing the distress of others.<sup>71</sup>

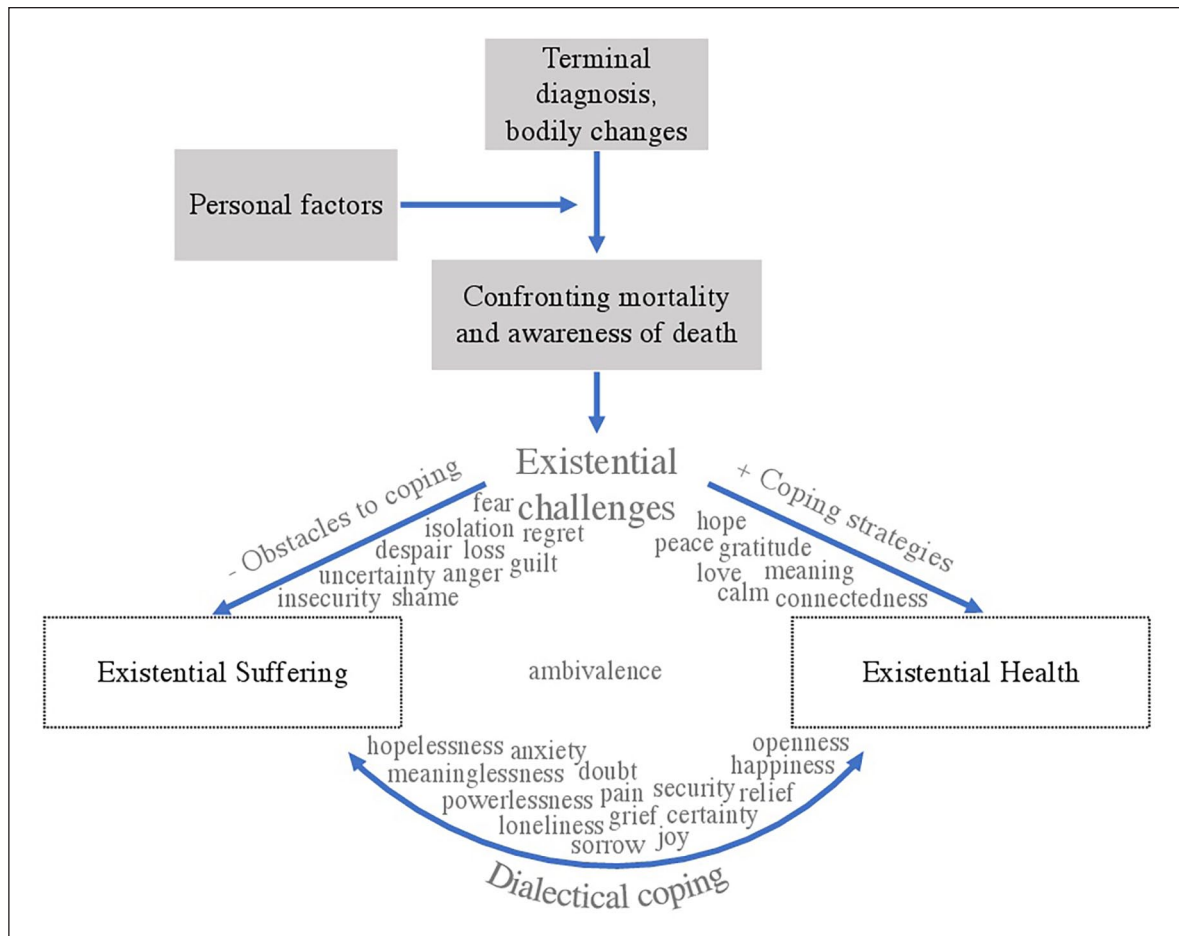
Moreover, the participants reported an improved sense of ego-integrity, feeling worthwhile, and having greater insight into their own personality as a result of life review interventions.<sup>65,83</sup>

## Discussion

### Summary of results

The aim of this review was to summarize evidence on the effects of confronting the finitude of one's own life. The meta-summary of 49 studies showed a variety of approaches of confronting finitude, including psychotherapeutic approaches, educational programs, and psychosocial narrative interventions. The majority of studies understood confronting finitude mainly as carrying out existing interventions; evaluations of individual coping strategies remain scarce. Moreover, the opportunity to learn from terminally ill patients and older adults and their heterogeneous and subjective experiences has not been fully utilized.<sup>89</sup> However, all the approaches show a clear trend toward producing beneficial effects in all evaluated outcome categories.

A model of the existential experiences of patients with cancer, developed by Tarbi and Meghani,<sup>90</sup> can be linked to our findings (Figure 2). The authors assume that, once a patient has received a terminal diagnosis, their awareness of their own finitude increases, and their confrontation with their own mortality is inevitable.<sup>90</sup> As a result of this destabilizing situation, existential challenges occur and can affect *existential health*. Existential health represents one end of a continuum and is characterized by finding meaning and the reframing of the self-concept, and has the potential to stimulate personal growth. At the other end of the continuum, existential challenges may lead to *existential suffering*, which is characterized by an inability to cope and a profound loss of self.<sup>91,92</sup> A person's tendency to move toward either health or suffering is influenced by their coping strategies. Drawing conclusions from our review,



**Figure 2.** Model of existential experience in adults.  
 Source: Tarbi and Meghani,<sup>90</sup> reprinted with permission of Elsevier.

coping strategies that might promote existential health could include an active confrontation with death-related topics in order to enhance overall well-being. As such, the aforementioned approaches represent a valuable form of support within psychosocial care.

Moreover, since old-age-related issues may also cause existential suffering comparable to the distressing situation that results from being diagnosed with a terminal disease,<sup>93–95</sup> this model may also be adapted to older people, especially those who feel closer to death.<sup>9</sup>

Previous research suggests that the positive effects of actively confronting finitude on measures of meaning coincidentally indicate a decrease in dignity-related distress.<sup>96</sup> The legacy documents commonly used as tools within psychosocial approaches seem to fulfill the patients' need to "feel significant", provide opportunities to speak about accomplishments in order to engender meaning, and thus preserve their dignity.<sup>77,97</sup> Since meaning and self-realization are the constituent elements of what is known as eudaimonic well-being, the effects of these factors are extensive.<sup>98</sup>

Facing the results of Orth et al.<sup>99</sup> meaning in life may decrease by the age of 60 or when experiencing existential concerns due to serious disease it is crucial to maintain or enhance one's meaning as a psychological entity in order to manage anxiety,<sup>100</sup> and to serve as a protective factor against depression.<sup>101,102</sup> Other variables such as social relationships and measures of self-concept can also be used to predict overall well-being.<sup>103,104</sup> Our findings support these interrelations and underline the importance of confronting one's finitude as a strategy for improving one's general well-being.<sup>105</sup>

In view of the demographic shift and the aging population, clinically challenging trajectories are becoming more complex. As a result of this, there will be a far greater need for end-of-life care.<sup>106–108</sup> Since well-being and all of the aforementioned related concepts are specific to each individual person, there is a clear need for patient-centered care based on the individual's wishes.<sup>109</sup> Consequently, patient-centered (palliative) care should not only focus on pharmaceutical treatment, but also include supportive

psychosocial strategies that will help to cope with the imminent death.<sup>110,111</sup>

### Strengths and limitations

To our knowledge, this is the first review on the effects of confronting finitude that is not limited to certain interventions or approaches or underlying diagnosis. Our results represent a broad perspective on possible approaches of actively confronting one's own finitude and their respective effects. The integration of behavioral and mental confrontation has scarcely been considered in previous research, and in particular there is a lack of research that focuses not just on people with a life threatening or life-limiting disease, but also on older adults, who are closer to death than younger population groups. Consequently, the results of this review are characterized by an imbalance toward terminally ill persons, and thus it may not be possible to generalize for older people.

In order to ensure the validity of the results presented in this review, we used explicit and comprehensive methods to identify and analyze relevant studies. Rigor was enhanced by means of robust inclusion criteria and appraisal of the included studies, which showed sufficient quality. However, there did exist a possibility of publication bias, the tendency to publish mainly desirable results. Moreover, the fact that the review was limited to studies written in English and German led to exclusion of studies published in other languages.

Although we avoided double reporting of findings by excluding the findings of primary studies in cases where said findings had already been reported in the included reviews, there may still be a risk of double reporting due to the fact that several of these reviews are based on the same primary data. Although the heterogeneity of the included study designs and approaches provides a comprehensive research overview, this might limit the validity of the summarized findings.

To date, there is no uniform definition of "confronting finitude", so the authors discussed and specified the characteristics of this term. Consequently, an active and direct form of confrontation, whether individually or in a group, or mental or behavioral in nature, was assumed, and it was decided that the topic of the end of life needed to be addressed directly.

### Conclusion

This systematic review presents a comprehensive understanding of the effects of different approaches of confronting one's own finitude, as well as possible determinants for well-being and emotional adjustments with regard to existential challenges in the shape of one's impending death. Our results provide an empirical basis for future research for supportive palliative care practices that go beyond

physical comfort. The opportunity to confront finitude and address existential questions should be a focus within patient-centered care, since the effects of such interventions within different outcome categories intersect with aspects of well-being. As such, low-threshold opportunities for broaching the issue of confronting finitude should be implemented.

Future research should further explore individual perspectives through qualitative research in order to consider individual coping strategies and experiential learning. Moreover, further investigations are required on the variety of approaches regarding the intended outcomes and mechanisms of action.

### Author contributions

All the authors contributed to this manuscript in terms of its conceptualization, methodology, drafting and editing, and have consented to the submission of this paper. The first two authors (HK & AH) contributed to the formal analysis and investigation. The first author, HK, was involved in the project administration and visualization.

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### Ethics and consent

Research Ethics Committee approval was not necessary, as this is secondary research in the form of a systematic review.

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### Data management and sharing

The included papers are available through their respective journals.

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## Appendices

### Appendix A. Search term for Medline via Pubmed and key concepts and key words for PsycINFO and Web of Science.

Nr.	Search words				
<b>Population</b>					
#1	elderly [Title/Abstract]				
#2	aged, 80 and over [MeSH Major Topic]				
#3	aged [MeSH Major Topic]				
#4	octogenarian [Title/Abstract] OR octogenarians [Title/Abstract]				
#5	nonagenarian [Title/Abstract] OR nonagenarians [Title/Abstract]				
#6	centenarian [Title/Abstract] OR centenarians [Title/Abstract]				
#7	“advanced age” [Title/Abstract] oldest [Title/Abstract]				
#8	“late age” [Title/Abstract]				
#9	“old age” [Title/Abstract]				
#10	“terminally ill” [MeSH Terms]				
#11	“terminally ill” [Title/Abstract]				
#12	“oldest” [Title/Abstract]				
#13	“life-limiting” [Title/Abstract]				
#14	“end stage disease” [Title/Abstract]				
#15	“life threatening” [Title/Abstract]				
#16	<b>#1 OR #2 OR #3 OR #4 OR #5 OR #6 OR #7 OR #8 OR #9 OR #10 OR #11 OR #12 OR #13 OR #14 OR #15</b>				
<b>Interest</b>					
#17	cope [Title] OR coping [Title/Abstract]				
#18	confront [Title] OR confrontation [Title/Abstract] OR confronting [Title/Abstract]				
#19	prepare [Title] OR preparedness [Title/Abstract] OR preparation [Title/Abstract] OR preparing [Title/Abstract]				
#18	deal [Title] OR dealing [Title/Abstract]				
#19	accepting [Title/Abstract]				
#20	awareness [Title/Abstract]				
#21	<b>#17 OR #18 OR #19 OR #20</b>				
<b>Context</b>					
#22	“finite life” [Title/Abstract]				
#23	end-of-life [Title/Abstract]				
#24	finitude [Title/Abstract]				
#25	finiteness [Title/Abstract]				
#25	dying [Title/Abstract]				
#26	death [Title/Abstract]				
#27	mortality [Title/Abstract]				
#28	<b>#22 OR #23 OR #24 OR #25 OR #26 OR #27</b>				
<b>Search term</b>					
#29	<b>#16 AND #21 AND #28</b>				
<b>Key concepts and key words for Web of Science</b>			<b>Key concepts and key words for PsycINFO</b>		
Population	Interest	Context	Population	Interest	Context
elderly (Topic)	cope (Title)	“finite life” (Topic)	elderly (Title, Abstract)	cope (Title)	“finite life” (Title, Abstract)
octogenarian or octogenarians (Topic)	confront (Title)	end-of-life (Topic)	octogenarian or octogenarians (Title, Abstract)	confront (Title)	end-of-life (Title, Abstract)

(Continued)

**Appendix A.** (Continued)

Key concepts and key words for Web of Science			Key concepts and key words for PsycINFO		
Population	Interest	Context	Population	Interest	Context
nonagenarian or nonagenarians (Topic)	accept (Title)	finitude (Topic)	nonagenarian or nonagenarians (Title, Abstract)	accept (Title)	finitude (Title, Abstract)
centenarian or centenarians (Topic)	prepare (Title)	finiteness (Topic)	centenarian or centenarians (Title, Abstract)	prepare (Title)	finiteness (Title, Abstract)
“advanced age” (Topic)	deal (Title)	dying (Topic)	“advanced age” (Title, Abstract)	deal (Title)	dying (Title, Abstract)
“late age” (Topic)	dealing (Topic)	death (Topic)	“late age” (Title, Abstract)	dealing (Title, Abstract)	death (Title, Abstract)
“old age” (Topic)	accepting (Topic)	mortality (Topic)	“old age” (Title, Abstract)	accepting (Title, Abstract)	mortality (Title, Abstract)
“terminally ill” (Topic)	awareness (Topic)		“terminally ill” (MeSH subject heading)	awareness (Title, Abstract)	
“life limiting” (Topic)	confronting (Topic)		“life limiting” (Title, Abstract)	confronting (Title, Abstract)	
life-limiting (Topic)	confrontation (Topic)		life-limiting (Title, Abstract)	confrontation (Title, Abstract)	
oldest (Topic)	coping (Topic)		oldest (Title, Abstract)	coping (Title, Abstract)	
“end stage disease” (Topic)	preparedness (Topic)		“end stage disease” (Title, Abstract)	preparedness (Title, Abstract)	
	preparation (Topic)			preparation (Title, Abstract)	
	preparing (Topic)			preparing (Title, Abstract)	

Refined to: categories: (psychology social or geriatrics gerontology or rehabilitation or health care sciences services or oncology or sociology or gerontology or nursing or psychology clinical or social work or psychology multidisciplinary or social issues or religion or social sciences interdisciplinary or health policy services or multidisciplinary sciences or psychology) and languages: (English or German).

**Appendix B.** Quality appraisal of quantitative and qualitative studies and reviews (based on CASP).

	Validity	Trustworthiness of results	Value and relevance
Aday and Shahan <sup>45</sup>	→	↑	→
Ando et al. <sup>46</sup>	→	↑	↑
Ando et al. <sup>47</sup>	↑	↑	↑
Aoun et al. <sup>48</sup>	→	↑	↑
Bentley et al. <sup>26</sup>	→	→	↑
Breitbart et al. <sup>49</sup>	↑	↑	↑
Breitbart et al. <sup>50</sup>	→	↑	↑
Chen et al. <sup>27</sup>	↑	↑	↑
Chochinov et al. <sup>52</sup>	→	↑	↑
Chochinov et al. <sup>53</sup>	↑	↑	↑
Dose et al. <sup>54</sup>	↑	↑	↑
Erlen et al. <sup>55</sup>	↑	→	↑
Fitchett et al. <sup>56</sup>	→	→	↑
Grewe, <sup>57</sup>	↑	↑	↑
Guerrero-Torelles et al., <sup>29</sup>	↑	→	↑
Haight <sup>58</sup>	→	↑	↑
Hall et al. <sup>59</sup>	→	↑	↑
Hall et al. <sup>60</sup>	↑	↑	↑

(Continued)

## Appendix B. (Continued)

	Validity	Trustworthiness of results	Value and relevance
Houmann et al. <sup>61</sup>	↑	↑	↑
Iani et al. <sup>62</sup>	↑	↑	↑
Julião et al. <sup>63</sup>	↑	↑	↑
Julião et al. <sup>64</sup>	↑	↑	↑
Kwan et al. <sup>66</sup>	→	→	↑
Lan et al. <sup>28</sup>	↑	↑	↑
Li et al. <sup>68</sup>	↑	↑	↑
Lo et al. <sup>69</sup>	→	↑	↑
Martínez et al. <sup>70</sup>	↑	↑	↑
Matsui <sup>30</sup>	→	↑	↑
Nissim et al. <sup>71</sup>	↑	↑	↑
Pautex et al. <sup>32</sup>	→	→	↑
Rosenfeld et al. <sup>72</sup>	→	↑	↑
Scarton et al. <sup>73</sup>	↑	↑	↑
Song et al. <sup>74</sup>	↑	↑	↑
Sopcheck <sup>75</sup>	→	↑	↑
Steinhauser et al. <sup>76</sup>	→	↑	↑
Steinhauser et al. <sup>77</sup>	→	↑	↑
Teo et al. <sup>34</sup>	↑	→	↑
Thronicke et al. <sup>78</sup>	→	↑	↑
van Gorp et al. <sup>79</sup>	↑	↑	↑
Vergo et al. <sup>80</sup>	→	↑	↑
Vig and Pearlman <sup>33</sup>	→	↑	↑
Vuksanovic et al. <sup>81</sup>	↑	↑	↑
Waldrop <sup>86</sup>	↓	→	→
Wang et al. <sup>82</sup>	↑	↑	↑
Xiao et al. <sup>83</sup>	↑	↑	↑
Xiao et al. <sup>84</sup>	↑	↑	↑
Zhang et al. <sup>85</sup>	↑	→	↑

→ Some of the checklist criteria have been fulfilled; where they have not been fulfilled or are not adequately described, the conclusions are unlikely to alter. ↑ All or most of the checklist criteria have been fulfilled; where they have not been fulfilled the conclusions are very unlikely to alter. ↓ Most of the checklist criteria have not been fulfilled.

## Appendix C. Quality appraisal of mixed methods studies (based on MMAT).

	Validity and trustworthiness qualitative data	Validity and trustworthiness quantitative data	Validity and trustworthiness mixed-methods approach
Brožek et al. <sup>51</sup>	↑	↑	↑
Kwan et al. <sup>65</sup>	↑	↑	↑
Lee et al. <sup>67</sup>	↑	→	↑

→ Some of the checklist criteria have been fulfilled; where they have not been fulfilled or are not adequately described, the conclusions are unlikely to alter. ↑ All or most of the checklist criteria have been fulfilled; where they have not been fulfilled the conclusions are very unlikely to alter.

## **Publication 2**

### **"My life became more meaningful": confronting one's own end of life and its effects on well-being-a qualitative study**

Helena Kukla, Angélique Herrler, Julia Strupp, Raymond Voltz.  
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RESEARCH

Open Access



# “My life became more meaningful”: confronting one’s own end of life and its effects on well-being—a qualitative study

Helena Kukla<sup>1,2\*</sup>, Angélique Herrler<sup>1</sup>, Julia Strupp<sup>2</sup> and Raymond Voltz<sup>2,3,4,5</sup>

## Abstract

**Background:** The perception of being closer to death can be experienced due to old age or life-limiting diseases, and can pose profound existential challenges. Actively confronting death-related issues and existential questions may increase psychosocial comfort and stimulate personal growth, whereas dysfunctional coping may lead to existential distress.

To date, research on individual and (semi-)professional approaches to confronting the own end of life and the effects on one’s well-being remain scarce. Therefore, the aim of this study was to explore individual strategies and wishes in order to derive ideas for appropriate support concepts.

**Methods:** Twenty semi-structured interviews were conducted with people over the age of 80 ( $n = 11$ ) and with a life-limiting disease ( $n = 10$ ). The interviews were transcribed verbatim and independently coded by two researchers according to Braun and Clarke’s thematic analysis approach.

**Results:** While the use of (semi-)professional approaches (e.g., therapeutic support) to confronting existential questions in the shape of one’s impending death was rare, individual coping strategies did have a positive impact on psychosocial comfort. There were hardly any significant differences between the participants aged 80 and over and those with a life-limiting disease in terms of individual coping strategies or how they approached the ends of their lives. Both groups reported that theoretical education, preparing for the ends of their lives (e.g., funerals), talking about death-related topics, reflecting on death-related topics, and contemplating death in a spiritual sense had positive effects on their assurance, self-determination and relief. The necessity of confrontation and a desire for low-threshold, accessible and flexible services to meet their existential and spiritual needs were highlighted.

**Conclusions:** There is both a desire and a need for the addressing of existential questions. Outside of private contexts, however, the participants possessed little awareness of support services that focused on confronting end-of-life issues, and rarely used such services. Efforts to raise awareness for psychosocial and spiritual needs should be implemented within the care system, together with low-threshold support concepts, in order to increase psychosocial well-being. More research evaluating individual approaches to confronting the own end of life are needed to better understand this determinant of well-being and its mechanisms of action.

**Trial registration:** [www.germanctr.de](http://www.germanctr.de), DRKS-ID: DRKS00020577.

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**Keywords:** End of life, Well-being, Quality of life, Palliative care, Aged, 80 and over, Coping, Attitude to death, Spiritual care, Qualitative research, Terminally ill, Finitude, Psychosocial support system

## Background

Natural aging processes and life-limiting diseases can be associated with declines in physical and mental competence, and result in an increasing awareness of the end of one's life [1–5]. Age and disease-related changes trigger the subjective perception of being close to death, and are therefore associated with mortality salience [6, 7]. The prominent Terror Management Theory addresses the pervasive role of the awareness of one's own end of life, which influences the psychological well-being. This can lead to high levels of discomfort and anxiety, rooted in the existential dilemma that death will ultimately occur [7]. Physical and mental losses and the related awareness of the impending death usually trigger existential questions that focus on the following themes described by Frankl and Yalom amongst others [8, 9]: finding meaning and meaning stagnation including issues of life and death and questions of the value of life connectedness, hope and anxiety [8–12]. These themes can be allocated to the overarching category “struggle to maintain self-identity” [12]. This challenging phase of life may cause existential suffering. According to the popular model of total pain concept of the 1960s, Cicely Saunders stresses the multidimensionality of pain and considers existential suffering as a result of meaninglessness [13]. The intactness of a person is threatened [14]. Meanwhile, the former connection between physical pain and existential suffering is debated intensively, but the existence of existential suffering is uncontroversial and perceived as relevant in health care settings [15]. However, research how to understand, manage and treat existential issues is needed [10, 16].

Consciousness of the impending end of one's life and therefore a lack of coherence and orientation requires a process of psychological adjustment of the self [10, 17, 18]. A resistance to change and the avoidance of one's finitude can result in dysfunctional coping strategies and increase distress [5, 7, 19], whereas an accepting attitude can decrease anxieties and help to ensure a good death [20, 21]. Current research shows that confronting death-related topics can also stave off distress and even provide capacity for personal growth [22, 23]. The process of adaptation enables individuals to progress toward an accepting attitude to death [6, 24].

The connection to spirituality, which is defined as the act of expressing and seeking meaning, purpose, transcendence and connections to others, oneself and a

higher power, can be a key aid in adjusting to the own end of life. Psychosocial and spiritual needs come to the fore alongside physical needs [10, 25–28] and are often interconnected with existential needs [29] and may even play the most important role within the field of healthcare [30]. The individual needs may neither be clearly assigned to spiritual nor existential dimensions, but are often intertwined [31]. Hvidt et al. [32] consider that “the existential” could represent an overarching concept including spiritual meaning orientations, but focusing less on transcendent aspects.

The need for psychosocial and spiritual care, that addresses the needs of people in their search for meaning in life, often remains unmet [30, 33–35]. The assessment and treatment of spiritual problems is established within the field of palliative care, but is given too little consideration within healthcare in old age and research [36]. In order to address individuals' uncertainties and their feelings towards death, dying and existential questions, person-centered holistic care must be provided [28, 37]. In other European countries, such as the Netherlands and the United Kingdom, spiritual care plays an essential role, and is therefore more easily accessible [37–39]. In Germany, however, spiritual and psychosocial support needs to be anchored more firmly in healthcare setting, and consequently in education for healthcare practitioners [40, 41]. Hence, there is a need to promote research, that includes spiritual needs, assessment and treatment of spiritual distress.

Although existential symptoms and spiritual distress are among some of the most debilitating issues, approaches to confronting these difficult demands and the underlying mechanisms of action have received little attention in research [10, 42, 43]. In particular, research based on individuals who are concerned with their impending death from a first-order perspective is generally under-represented [1, 2].

Previous research is based mainly on professional psychosocial approaches to confronting finitude, and contemplates the aforementioned issues to some extent, stating predominantly positive effects on psychosocial well-being that include relief, self-determination and assurance [44, 45]. Focusing on spiritual care, i.e., addressing uncertainties and feelings toward death and dying, as well as existential questions [28], can improve an individual's psycho-emotional stabilization, strengthen their self-identity and sense of purpose, and promote adjustment to death [17, 30, 43, 46].

Consequently, strategies to respond to these healthcare challenges unique to the end of life are needed in order to preserve quality of life for those nearing death.

The individual coping strategies and little-used (semi-) professional support concepts, which are understood as short-term interventions provided by trained personnel in some healthcare fields (e.g., nurses, psychologists), chaplains or skilled, trained volunteers, require further investigation and evaluation. As such, the aim of this qualitative study is to explore how people aged 80 and over or who have a life-limiting disease confront the end of their own lives, and how they experienced the effects of doing so. Wishes regarding the confrontation of one's finitude and potentially appropriate forms of intervention will be derived based on the results.

## Methods

This qualitative study was conducted within the Graduate School GROW – Gerontological Research of Well-Being at the University of Cologne. The reporting is based on the Consolidated Criteria for Reporting Qualitative Research (COREQ) checklist. Ethical approval was obtained from the Ethics Committee of the University of Cologne (approval no. 19–1617).

## Participants

The study focused on the section of the population with increased proximity to death due to old age or the diagnosis of a life-limiting disease. As a result, people aged 80 and over and people with a clinician-diagnosed life-limiting disease (no reasonable hope of cure and likely to cause premature death, e.g., cancer, heart diseases, neurodegenerative diseases) and able to conduct the interview were included in the study. People with cognitive impairments or limited ability to communicate were excluded.

Participants were selected purposely. Potential participants were approached with the help of healthcare stakeholders involved in the general care for the selected participants. These acted as entry points by recommending other stakeholders, and provided important both verbal and written information on the aim of the study, structural contexts and informed consent. In addition to this, participants were recruited via online channels, such as forums, email lists and newsletters. Participants were recruited until meaning saturation was reached and no new ideas or issues arose [47], i.e., the point where all the conceptual issues had been captured and the interviewees' meaning and insights were fully understood [48, 49]. We monitored the depth of data by documenting any new dimensions or insights of issues. After eight interviews and subsequent discussion, the conceptual scope of themes and codes was saturated, indicating that changes in the content of the codebook were completed. In order to establish sufficiency of conceptual depth and richness and diversity of data, we conducted and analyzed further interviews [50, 51].

## Study procedure and data collection

We developed an interview guide based on existing literature and a previous literature review [44]. The interview guide was discussed within the research team and pilot tested with one participant to ensure clarity and wording of questions.

The interview guide (see Table 1) was used to encourage participants to tell their personal stories and death-related experiences, as well as individual confrontation with their own finitude and wishes for opportunities to confront existential questions. The semi-structured design allowed us to be responsive to in-depth personal accounts using sub-questions intending to elaborate beyond the participant's initial response and rephrasing questions to elicit the pertinent information [52]. In

**Table 1** Interview guide

---

### Block I: Experiences

We're going to be talking today about the topic of death and dying. What experiences have you already had with death and dying?

What thoughts do you have when you think about the end of your own life?

How have you dealt with the finitude of your own life?

Having told us how you have dealt with this topic, what effect did this process have on you?

Recently, our lives have been marked by the Sars-CoV-2 pandemic, also known as Covid-19. I would like to talk to you about this. To what extent have you found yourself dealing with the topics of death and dying, especially during the Sars-CoV-2 pandemic?

To what extent have your attitudes towards dying and death changed as a result of the Sars-CoV-2 pandemic?

### Block II: Support for dealing with the issue

What specific support or services would you like to receive in order to confront the topics of dying and death?

### Block III: Conclusion

Is there anything else you would like to discuss or say on this topic?

---

order to convey meaning the interviewer diverged slightly from the script and motivated the participants to provide detail and clarifications. We adapted the interview guide in light of the current Sars-CoV-2-situation, and added two questions relating to changes of attitudes due to the pandemic.

In an initial conversation via telephone, the locations and scheduling for the face-to-face semi-structured interviews were chosen by the participants. The first author (HK), experienced in the field of end-of-life conversations particularly in hospice settings, provided information on the study, the interviewers background and pseudonymized data processing prior to the interviews. The participants were reassured that the interviews would be confidential and voluntary. Written, informed consent was obtained. Field notes were taken during the interview.

The audio of the interviews was recorded and transcribed verbatim using an external transcription service. The transcripts were checked by the first author and pseudonymized prior to analysis, and stored on a secure server. We provided the transcripts and results of the study to the participants on request.

#### Data analysis

Two experienced researchers (HK, speech therapist, and AH, health scientist), both of whom are experienced in qualitative data analysis, analyzed a core set of interviews using thematic analysis by Braun and Clarke [53]. This approach is an inductive method that allows emerging codes (single ideas associated with a segment of data) and themes (patterns of shared meaning) to be grounded in the original data. Both researchers were familiar with

the setting and AH was given information about the context of the interview including surrounding, initial conversations and perceived mood of the participants in a written form. Using a six-phase model (see Table 2), the transcripts were analyzed independently: [1] After familiarizing themselves with the data and forming initial analytical observations, HK and AH [2] independently coded a set of four interviews line-by-line. [3] Similarities and differences in codings were discussed and sorted into themes independently until a consensual codebook was developed. [4] Four further transcripts were then analyzed independently on the basis of this codebook in order to review and modify the themes and related codes. [5] After the differences between the two authors had been merged, a final version of the codebook was created as a result. This point was reached [6] Before the themes were interconnected and contextualized with the current state of research, the codebook underwent a final validation within the research team. After analyzing 50% of the transcripts independently and reaching data saturation the revised codebook was completed. Subsequently, all interviews were fully coded by HK based on the codebook. The coding of ambiguous parts in the interviews was double-checked independently with the second author (AH) and discussed until a consensus was reached [53].

#### Results

21 Interviews ( $n = 11$  people aged 80 or older and  $n = 10$  people with a life-limiting disease) were conducted between August 2020 and June 2021, lasting between 25 and 98 min each (see Table 3 for information on participants). The interviews were conducted in private without

**Table 2** Analysis procedure according to Braun and Clarke [53]

Steps	Procedure	Example
1. Familiarization	HK & AH independently: Reading and rereading the transcripts and noting down initial codes	Citation: <i>I think I have to act more responsible and forward-looking concerning the end of life. What keeps me busy is the elimination of things that I collected. That is my priority at the moment</i> (Interview 4: A, pos. 42) Initial codes: priorities before dying (HK), focus on essentials in life (AH)
2. Generating initial codes	HK & AH independently: Inductive coding line-by-line of four interviews	Independent coding: get things done (HK), before dying (AH)
3. Searching for themes	HK & AH independently: Checking and discussing codes for redundancies and sorting into themes	Related themes: feelings and attitudes to death (HK), the individual way until death (AH)
4. Reviewing themes	HK & AH independently: Modifying themes and generating a thematic map on the basis of four further interviews	Merged and modified theme: Before dying and agreed final code name: get things done
5. Defining and naming themes	HK & AH: Merging differences a final codebook was created and reviewed by AH	Discussing the revision of the codebook with AH and checking the related codings
6. Coding and reporting	Research team: Validating the final version of the codebook and independent coding of ambiguous parts of interviews by AH and HK	Proof or refinements of the whole research team



**Table 3** Information on participants

Number	Age	Gender	Participants aged 80 and over (A) and people with a life-limiting disease (D)	Setting
1	90	Female	D (cancer)	Home
2	89	Female	A	Senior care home
3	81	Female	A	Home
4	91	Male	A	Home
5	87	Female	D (cancer)	Hospice
6	88	Female	A	Home
7	80	Female	D (cancer)	Home
8	84	Female	A	Home
9	81	Male	A	Home
10	78	Female	D (cancer)	Home
11	83	Male	A	Home
12	97	Male	A	Home
13	87	Female	A	Senior care home
14	91	Male	A	Home
15	81	Female	A	Home
16	58	Male	D (cancer)	University
17	80	Female	D (cancer)	Hospice
18	70	Male	D (cancer)	Home
19	66	Female	D (cancer)	Hospice
20	78	Female	D (cancer)	Home
21	68	Male	D (cancer)	Home

distractions, and took place in each participant's location of choice: at the participant's home ( $n=16$ ), in a hospice ( $n=3$ ), in a care home ( $n=2$ ) or on the premises of the University ( $n=1$ ). In one case, the son of the interviewee was present. 11 main themes and 66 subthemes were identified (see Additional file 1).

#### Differences between people aged 80 and over and people with a life-limiting disease

No significant differences were identified between the two participant groups in terms of their approaches to confronting the end of their lives, their initiative and motivation to engage in confrontation, or their individual wishes for support in this area. In both groups, the participants who displayed more of a dismissive attitude did not necessarily avoid death-related topics; indeed, some of them explicitly mentioned the necessity of discussing these issues. For example, one participant avoided any contemplation of his life-limiting diagnosis: "So if someone says, yes, you are running away from it, then I think, yes, you could be right, you can see it that way." (Interview 16: D, pos. 66). However, he expressed an ambivalence toward his own perspectives "But that doesn't help, you have to talk about it. Otherwise, I don't know, then it will somehow get lost, because the process is not under control." (Interview 16: D, pos. 128). Within this interview setting,

the subjective perception of being close to death seemed to be comparable between the two groups. According to the participants, their attitudes toward death have not changed as a result of the pandemic, and most of them were cautious to avoid infection and the risk of dying from Sars-CoV-2.

#### Approaches to confronting the own end of one's life and their effects

In their narrations, the participants described a variety of approaches to confronting the own end of life: theoretical education, preparing for one's own death, talking about death-related topics, reflecting and thinking about death-related topics, and faith or and spirituality-based approaches.

##### Theoretical education

In both groups, theoretical knowledge regarding death and dying was often acquired through readings or literature. In some cases, the participants had also undergone further education on the topic on their own initiative. Theoretical education included films, Internet research with a potential focus on recent research results, and information sources such as physicians and specialized outpatient palliative care. This form of confrontation was usually chosen by the participants themselves, and often

led to assurance. This theoretical knowledge growth resulted in new coping strategies and the development of additional points of reference for the final phase of the patient's life.

*To find out what intellectual people have thought and written about it can lead to personal growth. (Interview 6: A, pos. 133)*

*So I found that very important, to put myself into context with other individuals. And not to think that things happen to me alone, they (...) are to do with development or with stages of life. (Interview 6: A, pos. 133)*

The described coping strategy in this difficult phase of life indicated that scientific knowledge has the power to provide certainty. The overall positive effects also included the relieving realization that others were in a similar situation, as one participant concluded.

*Ageing research (...) I find that relieving and reassuring, to see that it is part of it and that's how it is, and for you too. (Interview 6: A, pos. 137)*

### **Preparing for death**

Preparing for the end of one's life was inevitably a confrontation with individual ideas on how to actively take control over the final phase of one's life, and also an act of dealing with wishes for one's estate and burial. Participants with a life-limiting disease did not take more measures to prepare for the end of life than people aged 80 and over, though in some cases they did have more concrete ideas regarding their funeral process, e.g., clothing. In the context of advance care planning, most people in both groups had drawn up a living will and described a feeling of self-determination in that they could still make their own decisions up until their deaths, and that this made them feel more secure. A sense of relief and calming effect were also achieved following the completion of advance care documents. The feeling of knowing what end-of-life processes might look like helped the participants feel less burdened. Being proactive in terms of preparing for the end of one's life also played a role, in that many participants aimed to avoid being a social and emotional burden to others to stay as independent as possible.

*I don't want life-prolonging measures. (...) I've sorted things out so far, now we just have to let things come to us. (Interview 11: A, pos. 26)*

The planning of one's own funeral, the financing for which had also already been independently arranged in some cases, was occasionally perceived as threatening and strange, but the assurance achieved through detailed

planning, up to the clothing to be worn by the deceased, also had a positive effect in two ways: On the one hand, there was a feeling that "it's done" (Interview 3: A, pos. 154) and on the other hand, participants reported a sense of security that their funerals would meet their own expectations in writing.

*It was important for me to know that everything would be clean and calm and good. That those I write down are notified. (Interview 15: A, pos. 78)*

For other participants, planning was simply part of the process, and did not trigger any particular feelings.

*That's the way it is now. There is nothing more to say. I don't think about it all the time. That's how it is. (Interview 6: A, pos. 37)*

### **Talking about death-related topics**

The act of talking about death-related topics was mentioned frequently as a way of confronting the end of one's life. In most cases, the participants talked to loved ones about their current situation, the feeling of being close to death due to their age or health condition, and also about their estate and funeral. Death-related topics were also discussed with friends and healthcare professionals in order to help the participants orientate themselves within the final phase of their lives, to avoid illusions, and to share their own thinking, which help them feel more light-hearted. The effects of these actions were almost exclusively described as positive; participants said the discussion was helpful and important in developing their own coping strategies and alleviating their fears.

*Yes, you then feel... well, I did, at least... you then feel a bit lighter, because he had the same thoughts as I did. And so, he says, yes, we can't do anything about it anyway. It's our turn. (Interview 13: A, pos. 85)*

For some participants contemplating different scenarios with others could help to come to a neutral acceptance of the own end of life. Others described discussions of death-related topics more neutral in terms of their impact, as they possessed the conviction that death was a natural process and part of life. These participants also considered a discussion of their present circumstances and emotions unexciting but unavoidable.

The participants indicated that taking part in the interviews had enabled them to gain new insights, brought forward new concepts relating to attitude, and even resulted in improved satisfaction for them.

*I'm really grateful to you for this interview, because I wasn't aware of it at all. But it really comes more*

*from the fact that I have integrated myself like... (longer pause), yes, into the cycles on the one hand, into the natural cycles. (Interview 19: D, pos. 60)*

Conversations could also provide clarification and relief through the building of trust between conversation partners the compassion of the other person becoming visible to the participant. This acted as a form of reassurance that the participants were "not alone in this process of coping." (Interview 3: A, pos. 39) In addition to serious conversations, humor was also perceived as a source of relief in one case.

*There is a third person living there. That's the cancer. We named him Donald, after Trump, the ass. And if something went wrong or something, we said: I'm sorry, that was Donald. He is interfering again, the jerk. And that was helpful for me, to see it that way. (Interview 21: D, pos. 161)*

A few people said that they avoided conversations with the people closest to them, or only talked about such existential topics when the occasion arose, so as not to trigger burdensome situations themselves.

*My daughter never sees me like this. (cries) (Interview 5: A, pos. 102).*

This participant hid deep feelings and anxieties to protect her daughter from feeling responsible to handle such emotional situations but decided to carry the burden herself.

### **Personal reflections and thoughts**

Part of the confrontation the participants undertook with their own was largely invisible from the outside, as it took place within the framework of the participants' personal reflections and their own thoughts on topics such as fear of death, uncertainty regarding the future, and wishes for a dignified end of life. The participants often described feeling a sense of relief once they had established more clarity within their own thought processes and conclusions.

*I'm still too attached to life for that. But I am already thinking about how to defuse it. (...) To see it more calmly. The future of death, or what's in store for me. I have to accept that for myself. (Interview 9: A, pos. 181–183)*

It gave the participants confidence to believe in something and to develop their own path and attitudes. This had the potential to determine acceptance of phases of life. Participants rated personal reflections as a potential way of making life more meaningful. One unsettling

effect mentioned in very rare cases was thoughts of dying during sleep.

*(...) because I think about it and don't know what it's like, how it happens. That scares me. (Interview 2: D, pos. 37)*

Some people described having had little exposure to the existential issues of death and dying as they had not been present in their lives, the focus instead being on life-related matters. The effects of these initial thoughts were generally perceived as neutral and served as a source of reassurance, it was commonly assumed that confronting this topic was a necessity.

### **Spirituality and faith**

The participants reported turning to spirituality and faith to guide their approach to dealing with their own finitude. This approach was able to play a significant role in determining the individual's attitude toward death and dying. Several of the participants stated that believing in God and going to church helped to reduce their fear of death and dying and increase their well-being.

*I pray to Jesus often, and the Mother of God, and I say, "You know exactly what is good for me and I put everything into your hands," and then I have already really chosen a good number. Then I don't need to burden anyone else. (Interview 15: A, pos. 14)*

Mechanisms of actions seemed to be based on the conviction each participant had in their own beliefs and on external guidance from a higher power; this had a facilitating effect, as it led to the belief that one can only influence the course of one's life to a limited extent. Some people had turned away from the church without losing their faith. Spirituality was said to lead to an increase of assurance in terms of resonating with oneself and one's beliefs. People reported a greater sense of well-being and self-determination even diving deeper into spiritual topics, and said that this enabled them to integrate death into their lives.

*Then I go into the root system of the yew tree and that feels really nice. Yes, everything seems well-rounded and that's why I feel quiet... so especially with these ritual connections, I think that's what really helps me to feel good. (Interview 19: D, pos. 60)*

### **Need for action in confronting finitude and wishes**

Some people felt that settings in which there was an opportunity to review life and to discuss death-related topics strengthened a sense of meaning. Outside of private contexts, there were not many services that provided

low-threshold opportunities with a focus on confronting end-of-life issues. (Semi-)professional approaches to confrontation were difficult to access because they were not visible enough.

*It is important that this is made a bit more public – where people can find out about this, that and so on. (Interview 17: D, pos. 148)*

However, it was considered very important to remember that people are also entitled to avoid the topic, and for carers and people around those approaching the end of their lives to accept this opinion.

Therapeutic settings, including group therapy, were desired not only by people with life-limiting diseases, but also by people over 80 who wanted an honest discussion with others in their own age group. Psychological support services were requested, especially after a serious diagnosis, but there was also a desire for other forms of therapy, such as art therapy.

*Every tumor patient must be accompanied. That needs to be offered as a matter of course. (Interview 7: D, pos. 120)*

Being able to talk to one's next of kin, people in similar situations, and psychologically trained staff or pastoral caregivers was frequently mentioned as a need. Discussion groups were rated as desirable, but here too, a lack of accessibility was expressed.

Some people showed a great deal of uncertainty regarding what services currently existed, and for many people it was thus unimaginable to take advantage of services that focus on confronting finitude.

*I don't know. What kind of services are there? Yes, how, what can I wish for? (Interview 2: D, pos. 137–139)*

*But I don't know where else to look. (Interview 7: D, pos. 120)*

Some did not know whether they would make use of services, others categorically refused or expressed a diffuse range of ideas and wishes regarding the implementation of such services, since the idea of what contexts in which existential questions can be addressed might look like does not allow for inferable practical implications.

## Discussion

The aim of this study was to explore perspectives on confronting death and dying among people aged 80 and over and people with a life-limiting disease. No differences were found between the two groups of participants, so it can be assumed that the subjective perception of being close to death – and thus the experiences, attitudes,

issues, and the need to confront death-related topics – are comparable between both groups.

The confrontation with death and dying took place almost exclusively in private contexts rather than (semi-)professional settings, and included contemplating and talking about death-related topics, preparing for the end of one's own life, theoretical education, and faith-based approaches. Overall, the self-reported predominantly positive effects led to an improved sense of well-being and quality of life. This validates earlier findings. Spiritual needs for control, relationships, autonomy and a sense of purpose [54] can be fulfilled. Desires among these groups for further services remained relatively unspecific, as they had no clear idea of what contexts that focus on existential questions would look like. Options for discussion in both private and professional contexts were desired.

Emotional distress, be it spiritual or psychosocial in origin, should be treated with the same importance as physical distress [17], and there was a clear need for contemplating death and addressing uncertainties and feelings surrounding this topic [28]. Addressing death-related issues can open up dialogue with people who are more reluctant to talk about these issues [55]. The present study confirms this to some extent, as some of the participants wanted to talk about topics such as preparing to die despite describing themselves as avoiders, and even felt comfortable outside of their expected comfort zones during the interview.

The experiences of confronting the end of one's own life and the effects of the confrontation may provide insight into the determinants of general well-being for those subjectively nearing death. According to previous research, spiritual care may be a key aid in meeting existential needs; this includes being respectful, honest conversation, attention to overall well-being, and generally feeling affirmed and valued [18, 56], and can be provided by anyone [56]. The present interview study confirms that talking to one's next of kin or familiar persons may also ease worries regarding this situation. The participants' statements of gaining new insights as a perceived benefit of the research participation additionally highlight the positive effects of confronting this sensitive topic, even if only addressed within the research interview. Providing support may enable people who are distressed without realizing it to become aware of the roots and extent of their issues [18]. Even in healthy adults, spiritual interventions that focus on developing one's own perspective on death increase happiness and quality of life [57]. However, our participants stated that they hardly used any professional services; in fact, such services were not even known about, and were therefore not accessible.

Since needs and preferences at the end of life are highly individual and malleable, support and care systems need

to be accessible and flexible and offered as an invitation [17, 58, 59]. Patients need to be aware where they can seek assistance supported by health care providers or non-professionals who feel comfortable to engage in conversations about end-of-life issues such as dignity, meaning, autonomy and relationships [10, 18]. As such, awareness of spiritual and psychosocial needs among this population requires to be raised in order to provide customized support. The public support system also needs to be expanded, particularly with regard to the subjective perception among members of this group that they are a burden to the family members that assist them, which was also reported to be a major concern [60, 61]. An equivalent focus must also be applied to general social sensitization for public discourse that seeks to foster a strong culture of caring with respect to existential questions. Firstly, concepts relating to death and dying need to be included in the educational curriculum [62] within the field of healthcare. Therefore, the needed skill sets should be explored to inform training development. International guidelines to promote the field of handling existential issues within spiritual care inspired by existing guidelines like the National Consensus Project Guidelines [38] could expedite the introduction of existential topics within the care system and give caregivers security in practical application [31]. Secondly, more public relations work and low-threshold opportunities for confronting topics relating to death and dying need to be launched in order to draw public attention. To develop a profound knowledge base on the foundation of existing evidence community workshop and training programs should be expanded to develop competencies in spiritual and psychosocial care [63].

### Strengths and limitations

The participants were recruited from a variety of settings and different backgrounds, thus providing diverse experiences and views. With these interviews, we managed to open up a space for intimate and sensitive topics, and the respondents felt comfortable in spite of the emotional strain. Due to the first author and interviewer's proximity to the data, it was particularly important to ensure that said data was analyzed independently with the second author in order to ensure that none of the potential insights were overlooked.

However, the selection process did impose limitations, as potential participants were fully informed regarding the nature of the study and the topics they would be asked to elaborate on. As such, it can be assumed that the study sample consisted of people who would feel comfortable sharing their views and attitudes toward death, and were unlikely to avoid death-related topics. The life-limiting circumstances of those in the sample group were related

exclusively to cancer diseases, and participants in this group had an average age of 75 years. As a result, the possibility of an age and generation effect cannot be ruled out.

Since this qualitative type of study is based on a limited sample size, it does not seek to generalize results, but instead strives for an understanding of the particular context and to generate explanatory hypotheses. The transferability to similar contexts of existential discomfort is conceivable.

Furthermore, specific characteristics regarding economic status, educational background or religious beliefs were not pursued among the participants, as they were assumed to be of no significance. The sample represented the individuals to whom the results apply and matter, but it remains unclear whether the sample is representative of a larger population.

The Sars-CoV-2 pandemic impeded both the recruitment process and the conducting of the interviews, mainly due to restrictions on visitors. Nevertheless, it was possible to continue the project with the help of partners in practices and additional precautions and the finding of this study were not diminished or altered by the pandemic circumstances.

### Conclusion

The present study suggests that self-determination, a sense of dignity, and connection are all strengthened by confronting the finitude of one's own life, and may work as mechanisms of action for greater well-being. Pro-active coping processes tend to move a concern, distress or problem toward alleviation, or even resolution. As such, the act of confronting existential questions regarding life and death and the positive effects of this act should be incorporated into professional and informal support frameworks, and access to social and healthcare services, which is currently fragmented needs to be improved upon. This request applies not only to people with severe diseases, but also to those who feel an urge to talk about existential life issues, such as people aged 80 and over, or perhaps even younger.

Future research should focus on developing, implementing and evaluating supportive interventions that aim to increase psychosocial and spiritual well-being for people who are subjectively nearing death. A differentiation between life-limiting diseases other than cancer and changes in attitudes towards confronting the end of one's life across one's entire lifespan should be considered.

### Supplementary Information

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**Additional file 1.** Themes and codes derived from the data.

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**Authors' contributions**

Concept/design: All authors (HK, AH, JS, RV). Provision of participants: HK. Data acquisition: HK. Data analysis: HK and AH. Interpretation of data: All authors. Manuscript writing: HK. Critical revision of manuscript and final approval: All authors. All the authors participated sufficiently in the work to take public responsibility for the appropriate content. The authors read and approved the final manuscript.

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**Availability of data and materials**

The datasets generated and/or analyzed during the current study are not publicly available due to limitations of ethical approval involving the patient data and anonymity but are available from the corresponding author on reasonable request.

**Declarations****Ethics approval and consent to participate**

Ethical approval was obtained from the Ethics Committee of the University of Cologne (approval no. 19–1617). All the interviewees gave their written informed consent to participate. The study was conducted in accordance with the Declaration of Helsinki on Ethical Principles for Medical Research Involving Human Subjects (Declaration of Helsinki).

**Consent for publication**

Not applicable.

**Competing interests**

The authors declare that they have no competing interests.

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- 2) Kukla H, Herrler A, Strupp J, Voltz R. "My life became more meaningful": confronting one's own end of life and its effects on well-being-a qualitative study. BMC palliative care. 2022;21(1):58

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Helena Kukla