What would it take to die well? A systematic review of systematic reviews on the conditions for a good death

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The medicalisation of life under the influence of health-care systems, focused on curing diseases, has made dying well challenging. This systematic review identifies common themes from published systematic reviews about the conditions for a good death as a means to guide decisions around this universal event. MEDLINE, Embase, APA PsycInfo, and AMED were searched for citations with “good death” or “dying well” in their titles on Sept 23, 2020, and complemented with backward reference and forward citation screening with Google Scholar. Articles published in peer-reviewed journals in any language were included. Articles that focused on the identification of conditions for a good death and described how primary studies were sought and selected were also included. Data on general characteristics, quality, and themes were extracted independently. 13 of 275 potentially eligible reviews were included. Common themes were dying at the preferred place, relief from pain and psychological distress, emotional support from loved ones, autonomous treatment decision making, avoidance of futile life-prolonging interventions and of being a burden to others, right to assisted suicide or euthanasia, effective communication with professionals, and performance of rituals. No reviews specified the meaning or timing of death, connected themes, or prioritised them. Vague jargon was often used to describe complex concepts. Most conditions for a good death could be offered to most dying people, without costly medical infrastructure or specialised knowledge. Efforts to describe these conditions clearly, to identify whether there are exceptions or missing items, and whether they apply in non-dominant settings (ie, outside institutional, affluent, anglophone, and Christian settings) are needed.

Introduction

The COVID-19 pandemic made people notice one of the most neglected aspects of their lives: the conditions that are needed to die well. The implementation of large-scale physical distancing—seeking to flatten the curve while a vaccine or effective treatment became available—had unintended consequences, such as the hundreds of thousands of deaths in long-term care facilities, emergency rooms, and intensive care units, which were poorly prepared to match the expectations and needs of the population. The rapid increase in excess mortality in most nations in the world,1 within a relatively short period of time, resulted in what could be regarded as an echo pandemic of excess suffering, due to the exacerbation of old challenges and the emergence of new ones at practically all stages of the end-of-life journey.2 Either through their own personal experiences or via social media and 24 h television news, people became aware of the intense emotional pain caused by family separation, the prospect of dying alone, the inability to say final goodbyes, the coldness of virtual funerals, the views of refrigerated trucks at the back of hospitals, the pictures of mass graves, and the lack of supportive services for those left behind. The unprecedented exposure to the myriad sources of suffering at the end of life and to the overmedicalisation of life has created unique opportunities for efforts to redress long-standing gaps that separate how we would want to die and how we actually do. This awareness of death brought about by the pandemic has prepared the ground—societal, medical, political, and financial—to position palliative care as a central component of pandemic preparation efforts, rather than ignoring it during future outbreaks, as was the case during the COVID-19 pandemic.3,4

The rapid way in which the mortality associated with the COVID-19 pandemic increased throughout the world underscored the importance of efforts to understand and improve what humans should experience at the end of their lives.5 Screening of the biomedical literature identified a dearth of empirical studies during pandemics and a scarcity of a solid evidence base to make decisions about how to make a good death possible for anyone, and at any time. Instead, a single, unvalidated framework published in 1998 was uncovered,6 and a patchwork of systematic reviews examining the conditions for a good death within different populations, conditions, and settings. This study seeks to fill this gap with a systematic review of the evidence from such systematic reviews and identifying universal commonalities among them that could act as the foundation for efforts by policy makers, clinicians, researchers, and anyone else in civil society interested in improving the way we die, during pandemics and beyond.

Methods

Search strategy and selection criteria

In this systematic review, a search of MEDLINE, Embase, APA PsycInfo, and AMED was done on Sept 23, 2020, targeting citations with the terms “good death” or “dying well” in their titles, and restricted to reviews, with the filters available in the OVID platform. This search was complemented with backward and forward citation searching,7 by inspecting the references provided by the eligible reviews, and by screening the citations indexed for each of such reviews in Google Scholar.8 Articles were included if they focused on the identification of the conditions for a good death from the perspective of the dying person, loved ones, or the health
professionals involved in their care. Such articles had to be published in a peer-reviewed journal in any language and had to describe the process used to identify and select the primary studies they synthesised to be deemed eligible. Reviews were excluded if they focused only on the conceptual, administrative, managerial, or financial aspects of end-of-life care; or if they were described as reviews, without providing details of the process used to select studies for inclusion. Any conflicts about study inclusion were resolved with a team consensus.

Data analysis

Relevant information was extracted electronically in a predeveloped form, with Google Sheets, which allowed all authors (MZ, SE-A, AM, and ARJ) to construct the dataset simultaneously. The data extraction form was designed to collect the following data from each systematic review: first author, year of publication, title, institution of first author, country hosting the institution, funding source, search dates for review, databases searched, selection criteria, number of studies included, number and role of people included in studies, clinical conditions or diagnoses (whenever relevant), quality assessments, and prominent themes related to a good death or dying well. Information was also extracted about the context of the studies or attempts to conceptualise a good death with visualisation approaches.

Each of the eligible reviews was assessed by one of the authors (MZ, SE-A, AM, and ARJ) independently, whereas a second reviewer (MZ or ARJ) verified the judgements. With the critical domains of the AMSTAR-2 tool, the quality of these reviews was either regarded as high (with no critical flaws and zero or one non-critical flaw), moderate (no critical flaws or one non-critical flaw), low (one critical flaw with or without a non-critical weakness), or critically low (more than one critical flaw with or without a non-critical weakness).

For theme identification, where possible, text related to conditions associated with a good death was copied in its entirety, and pasted directly from the papers into the form, to minimise transcription errors. All data extracted were verified by MZ and ARJ, who also reread the full versions of the articles to ensure that all relevant themes proposed by a reviewer had been captured in the data extraction form, and that they were supported by the original text. Whenever there was discordance, the disagreement was resolved by consensus. Themes were deemed to reflect core conditions for a good death whenever they had been mentioned at least by two of the included reviews; and were relevant to decisions within a health-care system.

Results

A total of 275 papers were initially identified by the search strategy. After eliminating duplicates, 138 citations remained for further analysis. In the screening of these papers, 122 were excluded because of nonconformity to inclusion criteria and 16 papers were selected for full-text reading. After examining the full articles, three were excluded because they did not have a description of their selection criteria (figure). No additional reviews were found through inspection of the references cited in eligible reviews, or by screening the citations indexed for each of such reviews in Google Scholar.

One of the reviews was judged as high quality and three as moderate (table 1). The remaining nine reviews were considered to be of critically low quality, primarily due to the absence of justification for their exclusion criteria, and no bias assessment or effort to mitigate the risk of bias.

Altogether, 407 studies were featured by the 13 reviews (table 1), which focused on the views of dying individuals, bereaved family members, and health-care providers, all as key stakeholders in the dying process. Although two of these studies focused on general understanding of the good death concept, others targeted specific populations, such as children, anyone with terminal illnesses, older or frail adults with reduced agency, residents of long-term care facilities, the Japanese community, rural residents, or subgroups of the key stakeholders.

Most studies were done in the USA (n=7) and one study each in Canada, the UK, Australia, Colombia, and Singapore. Nine of the reviews limited their study selection to studies published in English. The only review not done in a high-income country was done in Colombia; its results were consistent with those of its high-income counterparts. None of the included reviews or the studies synthesised by the reviews focused on the implications of COVID-19 or any other pandemic.
Conditions for a good death
Several reviews recognised that the challenges associated with conceptualising or defining a good death stem, to a large extent, from the variable, continuous, and dynamic nature of life at the end.11,12,13,21,22 Four papers attempted to show relationships between attributes of a good death with an effort to conceptualise the phenomenon visually (table 1).12,13,21,22 Two studies focused on the timing of a good death, suggesting that the boundaries for the concept could start at the time of diagnosis or self-awareness of a terminal illness and that it could extend beyond the demise of a person,16 given the ongoing effect of death on the bereaved.21 In most cases, the description of themes was rich in technical jargon, which was used inconsistently among reviews.

| Country | Search dates | Databases searched | Selection criteria | Number of studies | Sample size | Population | AMSTAR-2 rating |
|---------|--------------|--------------------|--------------------|-------------------|-------------|------------|-----------------|
| Cottrell and Duggleby (2016)10 | Canada 1992–2014 | Cumulative Index of Nursing and Allied Health Literature, MEDLINE, PsycINFO, Academic Search Complete, and SocINDEX with full text and reference lists | Studies and articles that discussed a good death from a western perspective, published in English, and did not focus on suicide, euthanasia, or assisted suicide, or tested tools to measure a good death | 39 | 3591 | Multiple, including hospice patients, their relatives, health-care professionals, managers, and academics | OA: critically low; P: no; L: partial yes; E: no; RoB1: no; RoB2: no; MA: no |
| Kehl (2006)13 | USA 1995-2004 | PubMed, MEDLINE, Cumulative Index of Nursing and Allied Health Literature | Studies of adults identified with the keywords good death and a western perspective; studies focused on euthanasia were excluded | 42 | NR | General public, patients, family members, and health-care providers | OA: critically low; P: no; L: partial yes; E: no; RoB1: no; RoB2: no; MA: no |
| Chong et al (2019)16 | Singapore Up to May, 2018 | Embase, Web of Science, MEDLINE, Cumulative Index to Nursing and Allied Health Literature, and APA PsycINFO | Studies of dying in children with life-shortening conditions, including data on their perceptions, whenever possible, and those of family caregivers or health-care professionals | 24 | NR | Children with cancer, non-malignant disease, or several diagnoses | OA: high; P: partial yes; L: partial yes; E: yes; RoB1: yes; RoB2: yes; MA: no |
| Broden et al (2020)12 | USA 1998-2018 | PubMed, Cumulative Index of Nursing and Allied Health Literature, and Google Scholar | Nursing research on perspectives about end-of-life care, published as full-text files, in peer-reviewed, English-language journals | 18 | NR | Critically ill paediatric patients, dying in an intensive care unit | OA: critically low; P: no; L: no and partial; E: no; MA: no; RoB1: no; RoB2: no |
| Hendrickson and McCorkle (2008)10 | USA NR | MEDLINE, Cumulative Index of Nursing and Allied Health Literature, and APA PsycINFO | Studies that mentioned a good death and published in English, and included populations aged 0-18 years | 43 | NR | People diagnosed with cancer | OA: critically low; P: no; L: yes; E: no; RoB1: no; RoB2: no; MA: no |
| Granda-Cameran and Houldin (2012)16 | USA 1950–2010 | MEDLINE, Ovid, JSTOR | Studies identified by a literature search done with a combination of keywords: death and dying, quality care, concept exploration, and history, limited to humans and published in English between 1950 and 2010 | 49 | NR | Terminally ill patients | OA: critically low; P: no; L: partial yes; E: no; RoB1: no; RoB2: no; MA: no |
| Birchley et al (2016)10 | UK 1945–2015 | MEDLINE, APA PsycINFO, Cumulative Index of Nursing and Allied Health Literature, Cochrane Database of systematic reviews, Applied Social Sciences Index and Abstracts, AgeInfo, and selected specialised journals | Studies of frail older people, people with dementia or traumatic brain injury predominated (>75% of participants), or both, studies that reported original data on decision making related to end-of-life care in the community, care homes, or hospital, and studies written in English | 49 | NR | Frail older people, people with dementia, and people with severe traumatic brain injury | OA: critically low; P: no; L: yes; E: no; RoB1: no; RoB2: no; MA: no |
| Krishnan (2017)16 | Canada Since 1995 (published in 2017) | Cumulative Index of Nursing and Allied Health Literature, MEDLINE, and APA PsycINFO | Studies of adult populations in nursing homes and long-term care that attempted to define a good death, directly or indirectly, and published in English | NR | NR | Long-term care residents | OA: critically low; P: no; L: partial yes; E: no; RoB1: no; RoB2: no; MA: no |
| Hattoni et al (2006)16 | USA Up to March, 2004 | PubMed, EBSCOHost (Academic Search Premier, Alt HealthWatch, and Health Source), and MEDLINE | Studies of older adults’ experiences of a good death in a Japanese community, and published in English or Japanese | 44 | NR | Older adults | OA: critically low; P: no; L: partial yes; E: no; RoB1: no; RoB2: no; MA: no |
The themes extracted from the 13 reviews enabled the identification of 11 conditions for a death to be considered as good (table 2). These were, in order of frequency: relief from physical pain and other physical symptoms (n=13); effective communication and relationship with health-care providers (n=12), performance of cultural, religious, or other spiritual rituals (n=11); relief from emotional distress or other forms of psychological stress (n=10); autonomy with regards to treatment-related decision making (n=10); dying at the preferred place (n=9), not prolonging life unnecessarily (n=8); awareness of the deep significance of what is happening (n=8); emotional support from family and friends (n=7), not being a burden on anyone (n=6); and the right to terminate one’s life (n=2).

**Table 1: Characteristics and ratings of the studies included in this systematic review**

| Country          | Search dates | Databases searched                                                                 | Selection criteria                                                                 | Number of studies | Sample size | Population | AMSTAR-2 rating |
|------------------|--------------|------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------|-------------------|-------------|------------|-----------------|
| Rainsford et al  | Australia    | PubMed, Cumulative Index of Nursing and Allied Health Literature, Scopus, APA PsycINFO, and Web of Science | Studies published in English of rural residents with a life-limiting illness, including people dying and health-care professionals, and without age restrictions | 20                | 751         | Life-limiting illness such as HIV/AIDS, cancer, dementia, and cerebral vascular disease | OA: moderate; P: partialyes; L: partialyes; E: yes; RoB1: yes; RoB2: yes; MA: no |
| Meier et al      | USA          | PubMed and APA PsycINFO                                                            | Studies that defined or used a measure of a good death or successful dying, published in English; studies on euthanasia were excluded | 36                | 48          | Patients, their family members, and health-care providers | OA: moderate; P: partialyes; L: partialyes; E: yes; RoB1: yes; RoB2: yes; MA: no |
| Tenzek and Depner| USA          | APA PsycINFO, Academic Search Complete, MEDLINE with full text, APA PsycARTICLES, Psychology and Behavioral Sciences Collection, APA PsycTests, Social Sciences Full Text, EBSCO (Social Work Abstracts, SociINDEX, ALT Healthwatch, Communication and Mass Media Complete), Cumulative Index of Nursing and Allied Health Literature, Education Resources Information Center, and Health Source: Nursing/Academic Edition | Studies of bereaved family members or significant others following the death of a loved one | 14                | 368         | NR         | OA: critically low; P: partialyes; L: partialyes; E: no; RoB1: no; RoB2: no; MA: no |
| Krokorian et al  | Colombia     | Cumulative Index of Nursing and Allied Health Literature, MEDLINE, Embase, and APA PsycINFO | Studies published in English including the views of dying people, or the views of family members or staff about a good death from a patient’s perspective | 29                | 6690        | Patients    | OA: moderate; P: partialyes; L: partialyes; E: no; RoB1: yes; RoB2: yes; MA: yes |

NR—not reported. OA—overall assessment. P—protocol registered before commencement of the review. L—adequacy of the literature search. E—justification for excluding individual studies. RoB1—risk of bias from individual studies being included in the review. RoB2—consideration of risk of bias when interpreting the results of the review. MA—appropriateness of meta-analytical methods.

**Relief from physical pain and other physical symptoms**

Relief from pain and other physical symptoms was viewed as a hallmark of excellent end-of-life care by all key stakeholder groups. Its successful management might require a holistic approach encompassing management of emotional symptoms and spiritual care. Culture and religion might influence the importance of this condition, as some populations might prefer to not have all pain relieved and might find strength in enduring it.

**Effective communication and relationship with health-care providers**

Effective communication and relationships with health-care providers is also regarded as a hallmark of high-quality end-of-life care and reflects the desire for kind, compassionate, accessible, honest, and clear interactions, free of medical jargon, and with key sentences repeated, by patients, relatives, or providers, as necessary. Patients also sought the ability to comfortably discuss fears, spiritual beliefs, intimate concerns, and preferences for the dying process without being judged.
practices, and the compliance with food preparation and feeding, or the treatment of the body after death.

Relief from emotional distress or other forms of psychological suffering

Reviews underscored that the sociocultural roots of emotional or other forms of psychological distress go beyond physical issues, as they tend to emanate from financial hardship or from the unavailability of care outside institutional boundaries. These reviews also highlight the inter-relationship with other conditions, as distress often results from a paucity of knowledge about the dying person’s preferences regarding clinical decisions, which could threaten their autonomy, particularly in relation to the place of death.

Autonomy with regards to treatment-related decision making

Autonomy is a multifaceted condition, encompassing having a choice over the place and time of treatment, ensuring all available treatments are considered or used, and ensuring age-appropriate participation for children. Achieving this level of autonomy could be strengthened by effective advance care planning, particularly in western or anglophone settings.

Dying at preferred place

Although the reviews tended to emphasise the importance of dying at home, a place that has familiarity, comfort, and connectedness with loved ones, they also acknowledged that the options regarding the place of death narrow in accordance with the complexity of the terminal illness.
the perceived risk of becoming a burden, or the sense of helplessness among loved ones.2,15

**Not prolonging life unnecessarily**

Reviews recognised the difficulty of finding balance among enabling a natural death to occur and not prolonging life unnecessarily, the drive to extend life through medical interventions, and the need to respect the dying person’s preferences,11,13–18,22 while accepting that many believe that a higher power determines the time and quality of death.22

**Awareness of the deep significance of what is happening**

The realisation that death is imminent often encourages the dying person to have quality interactions with family and friends.7 This awareness also facilitates the opportunity to say goodbye, the completion of unfinished business, getting financial affairs in order, and attending to wills and other legal matters.8,9 Nevertheless, some studies have found that the opposite might also be valid, as being unaware of the impending end could be regarded as a condition for a good death, as it could minimise the risk of unnecessary psychological distress.10

**Emotional support from family and friends**

Having a caring group of family members and friends around for emotional support, bonded by a strong sense of connectedness and time to spend with each other was regarded as a key condition for a good death for both the dying person and family and friends,11,12,17–20,22 regardless of cultural background.18

**Not being a burden on anyone**

Dying without burdening the family was revealed as a condition for a good death by six reviews.11,13,18,19,20,22 Instead of encumbering their loved ones, research has shown that dying people value contributing to the lives of others, leaving a legacy, and being remembered in a positive way.7 The main sources of concern appear to be the creation of financial hardship or an overwhelming amount of demands on the physical or mental lives of their loved ones.11,18

**Right to terminate one’s life**

The right to end one’s life deliberately was identified as a separate theme (or mentioned as a key issue related to the extent of treatment preferences that should be considered),8 as important to enabling the dying person to remain in control,9 as a way to escape or abandon a medicalised dying process, or to control one’s fate while facing the inevitable end.10 Whether this condition could be met depends on whether euthanasia or medically-assisted suicide (or medical assistance in dying) is legally available and culturally acceptable.

**Discussion**

The 11 conditions for a good death identified in this systematic review reflect suffering that is probably a result of the growing medicalisation of life at its very end. Only three of such conditions, at best, require medical expertise or infrastructure: relief from physical pain and other physical symptoms (which in many cases could be achieved through simple means, outside institutional contexts), not prolonging life unnecessarily, and exercising the right to terminate one’s life. The remaining conditions reflect the need to reimagine ways in which the role of medicine could be downplayed, or other available resources diverted to enable those who are dying to have their desired and expected levels of psychological, spiritual, relational, communications, and practical support, regardless of their location, and socioeconomic and ethnocultural background.

Each of the conditions identified by this study should act as a source of guidance for an ambitious research agenda, which should be enriched by close collaborative efforts across traditional disciplinary, political, geographical, and sectoral boundaries. Such an agenda must be driven by the need to overcome the deficiencies revealed by the COVID-19 pandemic, which showed that the health-care system often contributes to people dying badly. By heeding calls to bring palliative care as early as possible to the core of pandemic preparation efforts, it will be possible to mitigate the myriad sources of unnecessary suffering that become even more visible during and after outbreaks. Just by ensuring the availability and rational use of personal protective equipment for loved ones would reduce, and perhaps eliminate, the distress that would otherwise be experienced by patients while dying alone or surrounded by strangers in an intensive care unit or nursing home. Similarly, securing an adequate supply of opioid medication to all patients could avoid, or reduce substantially, the distress caused by breathlessness and pain.7

This review of reviews also uncovered opportunities to pay more attention to the conceptual aspects of a good death, and to explore whether the only existing framework should be complemented, improved, or replaced.1 Special attention must be paid to the criteria that should be used to anchor a person’s death or the death trajectory, which none of the reviews addressed (only two described the timeline of the dying experience). Clarifying such criteria would improve the ability to establish and examine the boundaries for health-care intervention and the role that non-medical settings and stakeholders could play at the end of life. Nevertheless, the conditions revealed by the reviews suggest the existence of at least two layers that could be regarded as the determinants of a good death.8,9,21 The first layer would include factors that are associated or initiated by the dying experience itself, such as the ability to die in the place of choice or awareness of what is happening, whereas the second layer would involve pre-existing influential factors that could shape the experience, such as the beliefs and rituals associated with specific religions or cultures.
Each of these layers, in turn, include several interrelated elements that, in many cases, exert a crossover effect on the determinants. For example, economic status is recognised both as having a direct effect on the dying experience or as a pre-existing variable that would shape how a person would die.\(^{11,15,22}\) Addressing these issues would also require a greater appreciation by researchers of the need for a shared terminology to reduce the use of jargon or vague language, so that their efforts could be easily interpreted and incorporated into clinical, administrative, and policy decisions.

Another area that deserves attention is the level of agreement between the views of those who are dying and their loved ones, and those of the health professionals involved in their care. Specifically, none of the reviews identified or described attempts to ask physicians or nurses about the conditions they would like to experience at the end of their own lives for their deaths to be regarded as good.

Despite the strength of our meta-approach to identifying commonalities across populations, conditions, and settings associated with a good death, our findings were limited by the methodological weaknesses of the systematic reviews included, by the dominance of research done in high-income countries, and by the restriction of the scope to the perspectives of dying persons, their loved ones, or the health professionals involved in their care, mainly within health-care settings. Consequently, further efforts are required to generate knowledge about the extent to which the identified conditions for a good death would apply to humanity at large, particularly across political, religious, and cultural boundaries. It is also unclear whether the importance given by the literature to the place where death occurs, the desire for autonomy around clinical decisions, the means to end one’s life, or the ability to limit the use of life-prolonging measures reflects the institutional, affluent, western, anglophone, and Christian settings in which most of the research has been done. Arguably, it is reasonable to expect that what appears to be so consistent in such contexts could be the exception for the majority of humans. Therefore, given the inherent complexity of dying, and of living, reaching a consensus about the meaning of a good death or dying well might not be possible. This is compounded by the obvious fact that the determinants of suffering at the end of life, exposed even more sources of suffering at the end of life, despite all of these reservations and risks, it could be argued that clarifying the conditions of a good death and enabling every person to experience them, anywhere in the world and in any set of circumstances, was made even more urgent by the COVID-19 pandemic, which exposed even more sources of suffering at the end of life, as well as many fresh opportunities to ponder, discuss, and improve how we die, and, by default, how we live, in the 21st century.

**Contributors**

ARJ formulated the study design and literature search. ARJ, MZ, AM and SE-A assisted with data extraction and contributed to the data analysis and interpretation. ARJ and MZ wrote the manuscript.

**Declaration of interests**

We declare no competing interests.

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