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Measuring and monitoring the quality of dying in the UN Decade of Healthy Ageing

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WHO aims to identify metrics to monitor the quality of dying, complementing those indicators proposed under the UN Decade of Healthy Ageing. However, the proposed criteria for a good death are contentious. Needs and priorities vary between individuals and their carers, across conditions, over time, and across communities and cultures. Monitoring should also consider sudden or rapid deaths and assisted dying. Fundamental challenges in data collection include who reports, over what timeframe, and when. This Personal View explores these challenges, identifying potentially measurable indicators and ambiguities in their use, and offers recommendations towards a practical measurement framework. We aimed to define a concise, meaningful, and pragmatic set of indicators that could be collected and applied universally across countries and over time. We define a logic model of candidate variables at different conceptual levels and describe an empirical exercise for prioritising and operationalising these variables for measurement.

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Introduction

To monitor and evaluate the UN Decade of Healthy Ageing (2021–30), WHO has proposed a set of indicators of healthy ageing, based on functional ability and intrinsic capacity of older people.[1] Functional ability is defined as the health-related attributes that enable people to be and to do what they have reason to value. This definition could include individuals who are dying; however, specific indicators for this stage have yet to be developed. Mortality rates and life expectancy are important outcome indicators used to assess health-care system performance, with health-care interventions typically aimed at reducing avoidable mortality. Nonetheless, death is inevitable, and the importance of how we die has been widely recognised, for example, by the *Lancet* Commission on the Value of Death.[2] The period preceding death forms a part of the ageing trajectory and requires targeted actions to ensure that it is lived with the highest level of health and dignity. Dying well constitutes an integral component of healthy ageing.

Measuring the quality of dying can guide care and support for individuals who are dying and their families, inform clinical decision making, shape health and care delivery, support policy development and evaluation, facilitate comparisons across institutions and countries, and track changes over time across settings where people are dying and where end-of-life care should be accessible to them.

However, in attempting to identify such measures, numerous questions arise. How should a good death be defined? Who should report on the quality of dying? Over what timeframe should the evaluation occur? Which descriptors should be used? Should the assessment be performed prospectively or retrospectively? How do we take account of widely varying contexts, individual preferences, and sociocultural diversities? How can measurement and monitoring be implemented worldwide? The Decade of Healthy Ageing focusses on people older than 60 years,[3] although the principles that we describe might also apply at other ages.

How to define a good death?

A good death is an outcome or a moment that follows a period and process of dying well. The concept of a good death has been examined for centuries. Cassel argued that medicine should primarily aim to alleviate suffering,[4] whereas Saunders and Sykes emphasised a holistic approach to treat total pain—a combination of physical, psychological, social, and existential distress.[5] The US Institute of Medicine described a good death as one that is "free from avoidable distress and suffering for patient, family, and caregivers, in general accord with the patient's and family's wishes, and reasonably consistent with clinical, cultural, and ethical standards".[6] Additionally, several studies globally have defined a good death (panel 1). Although the definitions have much in common, such as the prioritisation of dignity, they show notable differences, for example, in the extent to which religious concerns are emphasised.[2,30]

The characteristics of dying well are debated. Especially in the context of cancer and other rapidly progressive illnesses, and in scenarios in which cognitive function is maintained, the features of dying well might include the following: death is anticipated; the individual is aware of and accepts it; death is peaceful and dignified, free from suffering, pain or other distressing symptoms; the person has control over treatment decisions; plans are made for future treatment, deteriorations, and the end of life; emotional, social, spiritual, and practical support is available from friends or families; the individual and their family gain a sense of closure, including the settling of affairs and saying goodbye; affordability does not influence treatment decisions or impose undue burden on families; and death

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Panel 1: Selected definitions of a good death worldwide based on research literature

Australia[7]
Includes themes such as strong community relationships, proximity to nature, access to appropriate palliative care, and the ability to die peacefully at home.

Bangladesh[8]
Described as a peaceful, painless passing, surrounded by family, perceived as a blessing granted by God and the outcome of a life well lived.

Canada[9,10]
Seen as a peaceful, planned, and dignified experience that reflects respect for the individual's life and values. A good death typically occurs in a familiar setting, surrounded by loved ones, and free from pain. In long-term care contexts, a good death also considers the unique needs of older adults with chronic illness or dementia, aiming to provide comfort, a sense of community, and a celebration of a life well lived. This experience highlights the care provider's responsibility to uphold dignity and quality of life until the end.

China[11]
Involves six key elements: absence of suffering, presence of companionship and care, absence of worry, preservation of dignity, acceptance, and reduced effect on family.

Colombia[12]
Centres on the ability of an individual to live and die with dignity, make autonomous decisions about their end-of-life care, including the right to choose euthanasia. The definition emphasises the importance of respecting the individual's life project (which refers to their personal vision of life and death) and ensuring their rights to a dignified death are upheld by health-care providers and the state.

Germany[13]
Defined as a death that aligns with the patient's values, wishes, and needs, ensuring dignity, absence of pain, a sense of control, and minimal emotional distress for both the patient and their loved ones. This includes having the right to make informed decisions, experiencing comfort, resolving interpersonal conflicts, and achieving a sense of meaning or closure.

Ghana[14]
Characterised as a peaceful, pain-free passing, marked by completing unfinished business, making peace with others, and accepting one's own death. Ideally occurs naturally, free from violence or traumatic illness, at home surrounded by family, and is embraced by loved ones. This concept encompasses social, psychological, spiritual, temporal, and spatial dimensions.

India[15]
Framed as a holistic experience that embraces dying as a natural and meaningful part of life. Emphasises relational, emotional, and spiritual dimensions that go beyond clinical care, aiming to maintain dignity, comfort, and interconnectedness with loved ones at the end of life.

Iran[16]
Described as a culturally and personally meaningful end-of-life experience that emphasises the dignity and individuality of the person. Involves passing away naturally, without invasive medical interventions that might diminish a sense of humanity or dignity. Spiritual and religious comfort plays a substantial role, ensuring that the individual's faith and beliefs are respected and supported. Additionally, a good death includes personal autonomy and participation in care decisions.

Japan[17]
Described as one that honours the individual's dignity, freedom from physical and emotional suffering, and fulfilment of personal values. Involves maintaining close family relationships, a supportive connection with medical staff, and spending final moments in a familiar environment. Key elements include a sense of life completion, control over one's circumstances, and minimising burdens on others. This experience also reflects cultural values of resilience, hope, and pride, emphasising meaningful contributions to others and spiritual fulfilment while allowing the individual to face death with peace and gratitude.

Jordan[18]
Emphasises the ability to die at home, which is regarded as a marker of quality in the end-of-life experience for patients with cancer.

Netherlands[19,20]
Highlights a dignified, peaceful process in which individuals maintain control over their end-of-life choices, including medical care and timing. Essential elements include awareness and acceptance of mortality, open communication with loved ones, living fully, addressing final responsibilities, and managing emotions effectively. Saying goodbye, being pain-free, and upholding dignity are highly

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Panel 1 (continued from previous page)

valued, as is avoiding unnecessary burdens on loved ones. The acceptance of euthanasia and other end-of-life options reflects a cultural emphasis on personal autonomy and compassionate care.

Philippines[21]
Recognised as an experience wherein the individual feels peace and readiness, without regret, and is assured that their loved ones are emotionally prepared. Includes being organised and prepared, ensuring that affairs are in order, and fostering family readiness to continue forward. Effective communication provides emotional comfort through compassionate care and virtual connections, and cultural and religious preferences for end-of-life rituals are honoured, even when adjustments are needed.

Saudi Arabia[22]
Prioritises religious and spiritual fulfilment, personal dignity, and the assurance of family security. Key elements include maintaining peace with God, ensuring that religious rituals are honoured, and providing emotional and spiritual support. Dignity, privacy, and a positive personal image among family and friends are highly valued, along with the ability to prepare for death through advance directives, saying goodbyes, and resolving conflicts.

South Korea[23]
Focuses on the ability of an individual to face death calmly and without fear. This perception is rooted in the belief that a good death should benefit both the individual and the family left behind. As individuals approach a life stage wherein death becomes more visible, older adults often express a passive hope for a death that does not impose a burden on others. Additionally, middle-aged individuals (25–59 years), who reflect on their own mortality while witnessing the deaths of important others, tend to express a proactive desire to leave behind a legacy of being a "good person", who is morally good and socially responsible.

Sub-Saharan Africa[24]
Describes the support of close family relationships and the care of community and religious fellowships, which help to fulfil emotional, social, and spiritual needs, and the acceptance from loved ones.

Thailand[25]
Involves a peaceful and natural process that is free from symptoms, characterised by acceptance and dignity, supported by an environment and social connections that foster readiness, and grounded in faith and religious values that bring a sense of peace.

Türkiye[26]
Defined as an end-of-life experience that aligns with principles of dignity, personal control, and quality medical care, considering both the individual's needs and the preferences of family caregivers. This concept emphasises the patient's sense of control over the dying process and the importance of compassionate and supportive care from health-care providers. Factors such as the presence of chronic illness, treatment types, and family circumstances shape the perceived quality of the experience, highlighting the need for empathetic and holistic end-of-life care.

Uganda, Kenya, and Malawi[27]
Emphasises effective pain control, respectful and dignified care, and assistance that enables patients to remain at home, alleviating physical, emotional, and financial burdens. Includes practical support and rapid access to clinical and social networks and a holistic approach to care with a strong focus on pain management.

UK[28]
Described as peaceful, dignified, and free from pain or distress. For patients, this definition includes dying quietly, possibly in one's sleep, and ideally suddenly without prolonged suffering. For health-care staff, a good death is characterised by effective symptom management, family presence, and an atmosphere of calm and comfort.

USA[29]
Characterised as a personal and adaptable experience that balances physical comfort, emotional peace, and personal values, ensuring dignity and respect. Key elements include effective pain and symptom management, the ability to prepare for and control end-of-life decisions, and achievement of a sense of life completion. This experience prioritises minimising burdens on loved ones, clear communication of treatment preferences, trust in care providers, and honouring individual spiritual and cultural beliefs. A good death often involves family presence, emotional and spiritual wellbeing, and the opportunity to leave a legacy, providing closure and a lasting affirmation of the person's life and contributions.

occurs in a place of the person's choosing. These priorities are supported by substantial evidence. Further proposed criteria include: not feeling like a burden, maintaining mental awareness, achieving a feeling that life had been lived well, fostering positive relationships with health-care providers, and access to medically assisted dying.[30–38]

However, this "good death script" has been criticised for potentially being unintentionally controlling or even damaging.[33,38–40] Some patients and families might feel coerced to comply with its assumptions, which might deviate from their preferences. These features of good death can be seen as idealised or privileged, depending on the support of others, availability of social and economic resources, and a suitable physical environment. Such features might be unavailable to much of the population, especially in low-income and middle-income countries and deprived demographics in richer ones.[41–43] Furthermore, some characteristics are inextricably linked to the sociocultural context in which they occur and are arguably western-centric. For example, in Japan, trust in health-care providers might be prioritised over active control of decisions. The importance of awareness, choice, control, autonomy, and family involvement might be interpreted differently between individualistic and collectivist societies, potentially comprising a large proportion of the world population.[44]

A substantial proportion of end-of-life care is provided by family members or non-professional carers, either by choice or necessity. Outcomes should recognise the relational nature of dying, and an additional aim of end-of-life care should be to improve carer outcomes. In low-resource settings, some so-called cultural norms and practices around dying might have developed due to a lack of alternatives—for example, the expectation of family care over professional care.

Moreover, the "good death script" does not adequately consider all deaths, including sudden death and rapid decline from an acute severe illness, which comprise approximately a third of deaths.[45] They are different from anticipated deaths and might represent a preferred trajectory of dying for some older people.[38] Medically assisted dying, representing up to 6% of deaths in some countries where it has been legalised, raises different questions about the quality of dying. In conditions such as dementia, frailty, and many chronic progressive disorders, accounting for most deaths in high-income countries, the start of the end-of-life period is uncertain, and dying can take years or decades. During this period, a focus on living well remains important. The dying well characteristics might appear to be premature, not fully applicable, or might represent components of good generic care, such as choice, access to health care, and social and emotional support.[46–48]

Cultural interpretations of death have also shifted over time, including traditional, modern, and postmodern perspectives. Traditionally, death was viewed as a natural part of life, with rituals and beliefs reinforcing ideas of community and continuity. Modern consideration tends to focus on extending life and managing death as a medical issue, with care outsourced to professionals. Postmodern perspectives support a diverse, individualistic view of death, emphasising choice and personal experience. These evolving perspectives highlight both the need to take account of cultural context and flexibility in end-of-life frameworks.

The definition of dying well will inform how it is measured. It might be impossible to define good death that holds across all populations, conditions, circumstances, and cultures. Rather than framing death as a binary outcome—good or bad—a "good enough death" might represent a more realistic if less aspirational, practical aim.[34,35] Alternatively, a focus on the period of dying, the type and quality of care delivered, and experiences during that time could be more appropriate, even if the start of this period is difficult to define. Monitoring and optimising quality of care is a related but distinct exercise, including at the end of life, and is the subject of complementary work by WHO.

In addition to considering what constitutes a good death, it is possible to define what constitutes not dying well. Indicators of not dying well might include deaths that are premature, avoidable, or violent; occur in isolation; with treatable but unresolved symptoms, functional loss, or mental distress; when communication or relationships are poor; with adverse effects from drugs or other treatments; in an undesired location; when medical treatments or care are unwanted or impose an undue burden on the patient, family, or other carers; or which result in financial hardship. Finally, social and structural inequities and discrimination can diminish end-of-life experience, reflected in levels of trust that different communities have in care provision.[2,37,49,50] A realistic measurement goal might be to avoid these "indignities",[51] which could be both easier to measure and more universally appliable than positive indicators of good death.

Who should report on the quality of dying?

Ideally, we should ask people who are dying about their care, experience, and evaluation of the care they receive. Unfortunately, most people who are close to death are likely to be ill, drowsy, cognitively impaired, unable to self-report, or unwilling to discuss their dying and death. In many conditions, the timing of death only becomes apparent when death is close or after it has occurred, making it challenging to identify who is actively dying, especially at a population level.[38]

Additional stakeholders—including family members, friends, health-care staff, organisations, and governments, all of whom might have different perspectives and priorities—are also important. The impact of dying on family and others can be profound and extends from the dying period through to bereavement. Family and other carers should be considered not only as stakeholders but also as partners in care. Their experiences and outcomes are valid additional metrics of the quality of dying. Saunders[52] argued that "the way we die lives on in the memory of those who survive", yet most indicators neglect the effects on families and carers.

Measurement often relies on families or other carers as informants. At the population level, assessment is most easily done after death using retrospective questioning—for example, through mortality follow-up surveys.[53] Data can include both the perceived experiences of the dying individuals and that of the informants. However, such reports might be subject to variable time delay after death, recall bias, especially if the dying period was stressful or exhausting, and could be shaped by the carer's own bereavement. Additionally, a bereaved carer might have incomplete knowledge of the dying person's experience, and views might differ by informants. Despite these limitations, a retrospective proxy approach to data collection is pragmatic and has been used in large-scale surveys of carer experience, such as the Views of Informal Carers Survey.[54]

Not all countries have universal death certification or registration systems. In countries without universal systems for death certification or registration, alternative methods such as verbal autopsy or social autopsy might be necessary.[55] Verbal autopsy typically aims at identifying the cause of death but could be extended to include physical symptoms, psychological distress, functional decline, circumstances, communication, and decision making. Social autopsy examines social, behavioural, and health system factors associated with a death.

An alternative is to ask health and care professionals, either about a specific patient or about care or services in general. However, this approach might not capture the subjective experience of the patient and might hide variability in care quality or systematic poor practices.[56] Poor recall is a particular problem when professionals report on the care of individual patients, especially if they have not known them for long. Additionally, professionals might idealise both care and patient experience.[38]

Audit-based approaches entail the comparison of recorded care with clinical practice guidelines at an individual patient level. This method is especially useful for discrete services, although large-scale national audits have also been undertaken.[45,57] Sentinel primary care networks have been used to evaluate quality indicators for palliative care using routine data.[45] Additionally, some studies have developed indicators using big data, including data linkages between electronic medical records, health insurance, death certification, and disease registries. However, these data are not available in all countries, so they are unlikely to be useful for cross-country comparisons.[58–60]

Over what timeframes should the evaluation occur?

Death is a single moment, which can only be known after the event. By contrast, the end of life represents a period of time, but defining and identifying the specific window is challenging. In the last days or hours of life, the approach of death might be almost certain, and the priorities of care might also be clear. However, a substantial proportion of deaths occur suddenly or follow a brief, acute illness without a recognisable terminal phase.

Conversely, individuals with chronic or progressive illnesses often have definable palliative care needs well before the last phase of life. For these individuals, essential actions to enable a good death should be addressed long before death occurs.[61] In such cases, a broadly palliative approach, focusing on patient needs and problems (rather than on cure), can comprise a significant proportion of care or can support concurrent curative, disease-modifying, or life-prolonging interventions. This approach might not necessarily involve specialist palliative care services.

One proposed definition of the end-of-life relies on diagnosis: the period after diagnosis of a life-limiting illness that precedes an individual's death, or after the withdrawal of active life-prolonging treatment, such as renal dialysis.[62] While some diseases are predictably and rapidly fatal, many are not.[63–65] Diseases, such as cancer or heart failure, might be amenable to disease-modifying or life-extending therapies over a protracted time course.[66,67] Over longer timeframes, both problems and priorities change.[68] The trajectory might follow a rollercoaster pathway, with crises and declines punctuated by periods of recovery and stability.[64,66] Patients with advanced cancer undergoing modern therapies could experience problems over many years associated with so-called survivorship.[69] Similarly, chronic conditions, such as degenerative neurological disease or frailty, require a combination of therapeutic approaches—including preventive care, acute care, mental health support, rehabilitation, and palliative therapies—over extended periods.[46] In these contexts, any approach that identifies people with advanced illnesses should adopt quality measures that work both for dying well and living well at the same time.[38,70] This approach "meets the diverse priorities of older adults, not just at the moment of death but during their last years and decades of life".[71]

The end-of-life period is sometimes operationalised as "when death is expected in the next 6-12 months".[62,72] Predicting the last 12 months of life prospectively is notoriously difficult, varies with different conditions, and, overall, is correct no more than half the time in practice.[73] The last 12 months of life might be a time of intensive, repeated, or prolonged medical intervention and expense. This care might be effective or ineffective, but that will usually be unknown in advance. A failed attempt at life-prolonging treatment does not necessarily reflect poor care; rather, the appropriateness of the proposed interventions should balance the chances of success, treatment burdens or harms, priorities of the individual, and available resources. Therefore, defining the care we should or should not deliver remains difficult, either in advance or retrospectively.[2]

The speciality of palliative care has long advocated the need for integration with other specialities, such as oncology, geriatrics, and primary care, as clear transitions from curative, disease-modifying, or life-prolonging therapy to palliative care are often neither possible nor clinically appropriate.[74] Consequently, selecting a timeframe for monitoring the process of dying is inevitably arbitrary.

Which descriptors should be used to measure the quality of dying?

The quality of dying can be conceptualised at the levels of structure, process, and outcomes.[75] A logic model is a visual representation of how an intervention is intended to work, connecting resources, activities, and desired outcomes.

Input or structure	Activity or process	Output	Outcome	Impact
Available resources: what needs to be in place	Actions taken: what needs to be done	Direct products of programme activities	Intended accomplishments	Change in organisations, communities, or systems
• Workforce (numbers, training) • Facilities (hospitals, hospice, homecare) • Policy • Legal framework (opioid availability, decision making, assisted dying) • Regulation • Funding • Government support • Compassionate communities	• Holistic and dynamic need assessment • Prognostication and prediction • Communication • Choice and shared decision making • Personalisation, tailoring • Advance care planning, legal proxy • Therapies (medication and non-drug approaches and specific and last days and hours of life care) • Psychological, social, spiritual, and emotional support • Coordination and continuity • Engagement and support by family and friends • Rituals • Physician-assisted dying • Quality improvement initiatives	• Awareness (of dying) • Acceptance (of dying) • Information across the trajectory of dying • Agency, relational autonomy • Goal-concordant care • Treatment burden • Optimised functional ability • Reduced unmet need • Resuscitation or do not attempt cardiopulmonary resuscitation rates • Accompanied dying • Preferred place of death	• Symptom control (physical, mental) • Patient experience, dignity, peace • Family carer experience and satisfaction (as carer and care recipient) • Mental health (patient and carer) • Quality of life, wellbeing • Reduced carer burden • Affordable care, avoiding impoverishment • Bereavement experience	• Public awareness • Public acceptance • Reduced fear of death • Better health-care efficiency, less waste • Improved services • Reduced inequities • Popular and political support
Equity*				

***Figure:* Initial logic model of potential candidate items or domains for measuring the quality of dying and end-of-life care**

*Equity is the absence of unfair, avoidable, or remediable differences among groups of people, whether those groups are defined socially, economically, demographically, or geographically or by other dimensions of inequality (eg, sex, gender, ethnicity, disability, or sexual orientation).[76]

Various candidate items for defining the quality of dying can be assembled into a logic model (figure): inputs (structure) describe service access, staffing, training, facilities, environment, competing priorities, and culture; activity (process) comprises care delivery—assessments, therapies, decision making, communication, and information given; outcomes comprise a good death or a death free from indignities; and impact describes the effects at the level of organisations, communities, health-care systems, or societies.

Targets can be developed for achieving structural and process-related goals to support implementation and monitoring. Good structure and process should provide the necessary conditions for good outcomes;[77] however, improved care will not always result in better outcomes.[53] Dying well will involve access to beneficial aspects of structure and process, as well as subjective responses to them (outputs) and some outcomes (such as displaying autonomy and freedom from pain), making it psychometrically complex.

Stewart and colleagues elaborated a specific end-of-life framework, including patient factors (diagnosis, clinical status, and available family support), structure, process, patient and family satisfaction with care (outputs), quality of life and dying, and length of life (outcomes).[78] Other formulations of health-care quality include outcomes, safety, and experiences;[79] access, appropriateness, acceptability, equity, effectiveness, and affordability;[80] or confidence in care, competence of care, resilience of care, and care that is valued by people.[81]

If outcomes are difficult to define or measure, it might be preferable to focus on structure and process, which correspond to quality-of-care measures.[43,71] Structure and process also represent aspects that can be directly influenced by specific interventions. For monitoring purposes, this dimension might be interpreted as accessing a specialist palliative care service. Palliative care is an approach that aims to improve the quality of life of patients with life-threatening illnesses and their families. An updated definition from the International Association for Hospice and Palliative Care emphasises the relief of serious health-related suffering: "the active, holistic care of individuals across all ages with serious health-related suffering due to severe illness and especially of those near the end of life. It aims to improve the quality of life of patients and their families and caregivers."[82] Palliative approaches developed for individuals with cancer have been extended to neurological conditions, dementia, advanced organ failure, multimorbidity, and frailty.[46,83,84] Virtually all health-care providers will care for people who are dying and should acquire appropriate expertise and competencies.[74] Accessing specialist palliative care services per se cannot define good quality; rather, the elements that define good care and resulting patient and family experiences, regardless of who delivers it, should be specified.

Descriptive measures of input or structure are relatively easy to collect, but there are ambiguities. For example, when considering generic facilities or generalist staff, the applicability of their training, competence, and confidence in delivering end-of-life care might be unclear. The extent to which law or health policy is applicable at the end of life or facilitates good care will often be unclear. Data on generic aspects of quality of care can be ascertained by survey or from routine data—for example, on whether certain items of information have been recorded, communication has been undertaken, or treatments delivered. Furthermore, some aspects, such as communication, might relate closely to outcomes like satisfaction or experience, while some aspects, like choice or decision making, emotional support, or observance of rituals, might be difficult to define or measure.

Numerous frameworks have been published describing essential domains of palliative care for care monitoring and evaluation. The US National Consensus Project for Quality Palliative Care (NCP) described eight domains (structure and process, physical, psychological, social, spiritual and existential, cultural, legal and ethical, and care of the imminently dying patient), each with an associated clinical guideline.[85,86] Bhadelia and colleagues identified five domains with 11 subdomains at the system level and two domains with 22 subdomains from the patient and family perspectives, which were used to develop a composite Quality of Death and Dying Index-2021.[37] De Roo and colleagues reviewed quality indicators based on the NCP domains and identified 17 sets of indicators comprising 326 different items.[87] The findings were used to generate a quality indicator tool (Quality Indicators for Palliative Care, Q-PAC).[60,88] Most indicator sets refer to specific patient groups (eg, individuals with cancer) or health-care settings (eg, hospices). Amador and colleagues mapped these indicators to a framework describing end-of-life care in dementia, highlighting both the complexity of assessment and the need for disease-specific considerations.[89]

Various scales measure the quality of end-of-life care at an individual level, although most are restricted to particular diagnoses. A review concluded that existing scales have some merit, but they are inadequate for use across settings or populations.[90] Some scales specifically assess the quality of dying as an outcome. A review identified inconsistencies in definitions and timeframes and insufficient cross-cultural validation or evaluation of sensitivity to change. All scales were proxy-completed, and response rates were generally poor. Almost invariably, the scales contained a mix of structure, process, and outcome items.[91–93] Further scales attempt to specifically measure the quality of life of individuals with very advanced diseases, with a focus on symptoms common in cancer,[94] and some disease-specific variants.[95] The Quality of Dying and Death questionnaire includes both quality-of-dying (outcome) and quality-of-care (process) metrics, comprising subscales for symptom control, preparation, connectedness, and transcendence.[96] The ICECAP Support Care Measure is a quality-of-life measure for use at the end of life, with seven items, including having a say in decision making, being with people who care, freedom from physical suffering, freedom from emotional suffering, having dignity and self-respect, support, and preparation. These are positively framed with a simple response set, providing a viable, valid, brief measure with associated preference weights.[97,98]

Experience and satisfaction can be questioned or observed in real time, potentially over a prolonged period, but might become more difficult when close to death. Both can be ascertained retrospectively via an informant. Services are increasingly regulated and inspected, leading to increasing emphasis on integrating quantitative indicators with narrative evaluations. Measurement of bereavement experience will require further multidimensional consideration.

Some impact measures might be measured by periodic attitudes surveys. However, factors such as efficiency, overall service quality, and political support could be influenced by multiple variables, and changes will be difficult to attribute to end-of-life provision per se. Measuring the cost and impact of inaction might also be helpful. Furthermore, early palliative care can result in less aggressive end-of-life care, which has implications for individual health outcomes and potential cost-savings for the health system.

The identification of key performance indicators and their use in system-wide quality improvement drives a tendency for care to follow indicators rather than needs. Nevertheless, this indicator-driven approach can lead to unintended consequences. Two examples are place of death (with transfer to nursing homes from hospital shortly before death to avoid hospital deaths) and advance care planning (in which inadequacy of options and oversimplification leads to tokenistic or tick-box completion).[99]

How do we take account of widely varying individual contexts, preferences, and types of death?

A key feature of good end-of-life care is respect for individual preferences and priorities, which vary and are dynamic. Expectations, experience (especially of previous deaths of family or friends), and the need to prioritise or trade-off different preferences influence what is important to a particular individual.[100] Individuals also vary in how they wish to make end-of-life decisions.[101] Individualised assessment and care planning should consider this variation.

Given the vulnerability and frequent cognitive impairment at the end of life and varying ability to form and express opinions, emphasis on individual autonomy might not always be appropriate. Decision making should instead be considered within a social and familial context, often referred to as relational autonomy.[102]

Symptoms and problems differ between individuals and patient groups, according to diagnosis, care setting, and type across the physical, mental, functional, or social domains. These differences might arise from the underlying pathology, comorbidities, treatments, or treatment complications. Some problems could be difficult or intractable without easy or effective therapeutic options (eg, fatigue, incontinence, or dementia-related distress). This variability in symptoms and concerns makes the measurement against quality standards difficult, as the same care might be good or bad, depending on context. The most appropriate care might include different interventions over time and cannot necessarily be judged against the resolution of symptoms. Furthermore, some circumstances, including poverty, pandemics, wars, and famines, almost preclude the achievement of dying well, but these factors often lie outside of the jurisdiction of health services.

Different goals might not always be compatible, or tensions can arise between them—for example, controlling pain at the expense of awareness or transferring a patient to the hospital when home circumstances do not allow the delivery of basic nursing care. Patients and families might hold different care goals, and these might change over time.[100]

Dying, death and grief are culturally significant experiences associated with deep-rooted beliefs, interpretations, expectations, and rituals. While many cross-cultural similarities exist, this dimension cannot be ignored. Some commentators argue that the experience of dying is so intrinsically personal that measuring the quality of dying is impossible.[33,38,71] However, synthesising aggregated experiences can help us to better understand and potentially improve the process of dying despite the wide spectrum of sociocultural diversities and individual characteristics.

Equity between different social and demographic groupings should also be considered.

Monitoring the quality of dying worldwide

Specific goals of monitoring are to improve the quality of care at the end of life, enhance the experience of dying, and support as many individuals as possible in achieving a good death in whichever way they and their families, friends, or communities define it. Indicators must serve these purposes.

Despite conceptual and practical difficulties, the absence of consensus should not prevent efforts to select items or measurement tools and implement them. Measurement processes highlight and foreground key areas that might otherwise be neglected in policy and service delivery. Measurement and monitoring can help to drive improvement, assurance of standards, and address inequities. Service improvement is required now, and postponement of monitoring might delay the necessary reforms. Nevertheless, awareness is required that proxy measures can reshape care delivery in ways that are unintended or unhelpful. Experience with the application of measurement tools will contribute to their evolution and improvement.

International public health initiatives require well-defined indicators that are valid, reliable, and simple enough to deliver at scale, including in low-resource settings, thereby enabling reliable benchmarking. Global measurement should fulfil certain criteria, including valid representation of patient and family voices; universal or widespread applicability and availability; low cost; availability from routine data or feasible collection (including in low-resource settings); adequate psychometrics to enable differences or changes to be described; cross-cultural relevance; suitability for setting targets for improvement; and the ability to support regular tracking and timely adjustments of performance targets.

The need for brevity and universality largely excludes the use of specific quality of dying measurement scales. However, identifying key items or standards of care that most people would agree are worth striving for is still possible, even if not comprehensive.

Comparison is a powerful tool for improving the performance of health systems and achieving quality targets, and it carries political and journalistic impact. In 2015, the Economist Intelligence Unit published an assessment of end-of-life care in 80 countries worldwide, using a balanced scorecard approach that combined the publicly available data and country expert opinion.[103] Although the scorecard used arbitrary scoring on selected dimensions, the framework enabled widespread comparison.

Finkelstein and colleagues used a different methodology to grade and rank 81 countries' quality of end-of-life care based on 13 indicators and preference weights from carer-proxies of recently-deceased individuals to generate a preference-weighted summary score.[56] The findings revealed a strong association with economic development and considerable variation within country-income groups.

Expert meeting report

An online expert meeting was held on Nov 27, 2024, comprising 33 participants from the authorship group and representatives of WHO and the UN, including all WHO regions. Participants were invited to select items describing attributes of dying well and not dying well through a structured ascertainment process. The identified attributes were thematically analysed using frameworks derived from previous literature. 220 attributes were identified and classified into eight domains (table): (1) personal autonomy, control, and planning; (2) medical and symptom management; (3) psychological and emotional support; (4) social and cultural considerations; (5) information and communication; (6) quality and accessibility of care; (7) legacy and closure; and (8) circumstantial and uncontrollable factors. These domains broadly align with the existing literature and form an initial priority list. Further examination is required to determine their measurability and actionability.

Conclusion and a practical proposal

We propose a working definition of the quality of dying as the extent to which a person dies in a manner consistent with their values and preferences, taking into account their culture, goals, expectations, relationships, and concerns around life and death.

The concept of quality of dying will benefit from measurement, monitoring, and scrutiny from an international public health perspective. Nonetheless, several challenges exist—appropriate end-of-life care is both variable and context-specific; a consensus on when dying begins and what constitutes a good death is lacking; measurement is inherently difficult; and no single variable or scale can adequately measure a good death, quality of care, or quality of dying across diagnoses, contexts, and cultures.

Given these complexities, we should consider an approach that addresses multiple components in a complex system from which sample items or domains can be used to

	Dying well	Not dying well
Personal autonomy, control, and planning	Having a voice and agency in decision making about where and how to die Having the option of assisted dying Dying in a way that respects one's identity Having care goals met Being able to take decisions about care	Voice and wishes not being heard Feeling pressured to choose assisted dying Being repeatedly asked about care choices Lacking the opportunity to say goodbye or resolve issues in relationships
Medical and symptom management	Having adequate symptom control Experiencing pain that is tolerable Avoiding medical care that is futile or offers minimal benefit Having timely access to palliative care	Experiencing pain or severe discomfort Enduring prolonged suffering Lacking access to effective pain relief Receiving futile treatment that does not improve quality of life Dying with intensive medical support against one's wishes
Psychological and emotional support	Feeling respected, heard, and supported Receiving support to address death-related anxiety and existential distress	Enduring death-related anxiety and fear Feeling afraid, alone, or isolated Experiencing existential angst
Social and cultural considerations	Being surrounded by loved ones Having culturally relevant rites and rituals respected Including families of choice in the dying process	Experiencing a lack of respect for culture or rituals Dying alone or separated from loved ones Having spiritual needs unmet
Information and communication	Family having the information needed to prepare and provide support to the dying person Having sufficient information around prognosis and care options Receiving compassionate and person-centred communication	Feeling that more information might have led to different choices Not knowing what is happening Feeling unprepared Receiving poor communication from care providers
Quality and accessibility of care	Receiving coordinated and continuous care Having trust in care providers Receiving care that aligns with personal preferences	Receiving poor quality care Undergoing treatment that is not in accordance with one's wishes Receiving care that imposes a burden on family caregivers Facing inequities in access to end-of-life care
Legacy and closure	Hoping to be remembered as a good person Saying goodbye to loved ones Achieving closure with unresolved issues	Leaving behind unfinished business Worrying about the impact on dependants Experiencing unresolved family conflict Fearing that no one will mourn one's passing
Circumstantial and uncontrollable factors	Experiencing a sudden death that is still of good quality due to advance planning and preparation	Dying in an active war zone Dying in a disaster situation (eg, due to climate change) Experiencing a sudden death without preparation or closure Experiencing premature, avoidable, or violent death

Table: **Domains and attributes of quality in the dying experience summarised from the results of an expert consensus exercise**

Panel 2: Key considerations for measuring and monitoring the quality of dying

- Globally applicable metrics are necessary to monitor the quality of dying and to inform health-care system improvement
- Definitions of dying well or a good death vary across health conditions, individuals, cultures, and time, and must account for sudden deaths and assisted dying
- Definitions of dying well must reflect the differing and evolving contexts, needs, and priorities of individuals
- Quality of dying is defined as follows: the extent to which a person dies in a manner consistent with their values and preferences, taking into account their culture, goals, expectations, relationships, and concerns around life and death
- A core set of indicators can be defined to reflect both dying well and not dying well with adequate generalisability. These indicators might include metrics based on the experience of the dying individual and the satisfaction of family members or other caregivers
- Data collection can be challenging because of the arbitrary nature of the dying timeframe, limited ability or willingness of dying individuals to self-report, and the involvement of multiple stakeholders. Retrospective proxy reporting might be required
- No existing framework or scale is entirely adequate for data collection for the measurement of quality of death
- A logic model can be developed to define inputs, activities, outputs, outcomes, and impacts, as well as to describe a range of important quality markers

measure and monitor the process of dying well (panel 2). This framework might include negative items (indignities) which should be avoided. The initial step will involve prioritising the items to measure, followed by further work to operationalise those items effectively.

Ascertainment of the quality of death, at least initially, will likely rely on family members after death, using mortality follow-back surveys or verbal autopsy. We suggest that the primary timeframe should focus on the last week of life, with consideration also given to the last 3 months, albeit with potentially different indicators, while accepting that these timeframes are arbitrary. The last week is temporally immediately relevant to the death but offers an inadequate perspective. The last 3 months acknowledge the longer timeframe while minimising the ever-increasing complexities that accompany longer periods.

Two key dimensions, both reported after death by family or other informants and mostly generalisable, are proposed: (1) the perceived experience of the person who is dying prior to death, including symptoms, suffering, and distress in multiple dimensions and (2) the satisfaction of family members or other carers regarding the way the person died and the care delivered.

However, these dimensions are neither perfect nor comprehensive. Additional structural and process measures of workforce training, legal and policy framework to facilitate end-of-life care, communication, decision making and control, treatment burden, unmet need, indignities and inequities, and carer burden should also be incorporated. The development of these domains requires collaboration with individuals and families from diverse backgrounds in choosing and refining measures.

The prevailing narrative of dying well has already influenced societal thinking and health service responses, mostly favourably. However, this narrative might also have distorted philosophy and provision in some respects. Future measures need to consider multiple causes of death, including sudden and rapid deaths and those related to chronic conditions such as frailty, dementia, multimorbidity, and advanced organ failure, and the broad spectrum of events and circumstances accompanying the dying process. A balanced approach will require acknowledging unintended consequences, interpreting data intelligently in light of critiques, and introducing balancing measures to monitor for negative effects in other areas of care.

Contributors

RHH, JAT, ABh, CRM, CM, ELS, EAF, JTvdS, JV, LVdB, MM, MG, SH, and AO conceptualised the study. RHH, JAT, TZ, and ABa supervised the project. RHH and JAT were involved in project administration. RHH and JAT contributed to the study methodology. RHH, JAT, ABh, CM, EAF, and MY were involved in the investigation. JAT and MY performed the formal analysis. RHH drafted the manuscript. JAT, ABh, AF, CRM, CM, DB, ELS, EAF, HS, JW, JTvdS, JV, LG, MF, MD, MM, MG, SH, SL, RS, MC, YS, AO, TZ, and ABa revised the manuscript.

Declaration of interests

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