Journal of Integrative Nursing and Palliative Care (JINPC)

Volume 6 | Issue 2 | Page 232-241

Original Article

Psychometric Validation of the LED Good Death Index in Patients with Terminal Cancer: A Mixed-Methods Study

Bruno Martins[1]*, Lucas Pereira[1], Renata Azevedo[2], Pedro Costa[1]

[1]*Department of Integrative Clinical Nursing, University of Minho, Braga, Portugal.*
[2]*Department of Palliative and Community Care, University of Porto, Porto, Portugal.*

Abstract

Individuals facing terminal illness commonly endure considerable physical and mental distress. This suffering influences the patients directly as they cope with the pain of their disease, as well as their family members, who are impacted by the patient's condition and related medical choices. In addition, investigating how patients and their families perceive a "good death" is key to reflecting on the meaning of life and to designing appropriate treatment or care approaches (such as advance care planning). As a result, gaining insight into these matters is vital for advancing palliative care services and improving patients' overall quality of life. The purpose of this study was to create a clinical assessment instrument that allows patients with terminal cancer to evaluate for themselves whether they are moving toward a good death. The concept of a good death used in this work was constructed through detailed interviews with terminal cancer patients, combined with qualitative analysis performed by specialists in a dedicated research program. Three core themes emerged from the analysis: "living in dying (L)", "experiencing the existential self (E)", and "dying in living (D)." Based on these, the principal and co-principal investigators developed the initial LED Good Death Index (LED-GDI) using the three main themes together with the 15 subtopics that define the LED Good Death concept.

In total, 144 participants finished the LED-GDI assessment. The Cronbach's alpha coefficient for the LED-GDI reached 0.854. Findings indicated that the LED-GDI successfully enabled patients to determine whether they were approaching a good death. The underlying philosophy of the LED-GDI resonates strongly with Confucian traditions in East Asia and stresses the value of living meaningfully before death. Consequently, the primary aim of clinical end-of-life care should be to establish whether patients suffering from terminal illness can experience a good death while remaining fully alive until their final moments.

Keywords: Attitude to death, Existentialism, Good death index, End-of-life care

Introduction

Ensuring a dignified and positive end-of-life experience for every individual has become a key focus in both societal discussions and government policies. Achieving this goal requires robust training programs and ongoing education for healthcare workers to conduct detailed appraisals of end-of-life services and make the best possible use of available resources [1]. What counts as a good death remains highly personal and is shaped by a person's unique background, including cultural, social, political, and spiritual beliefs [2]. In East Asian societies, where Confucian and Buddhist philosophies have long influenced thinking, ideas about a good death contrast sharply with those commonly found in Western traditions [3–6]. Nearly all existing psychometric instruments used to measure a good death were originally built upon contemporary Western theoretical models. Although a few studies have introduced cultural adjustments, it is still important to create and apply tools that emerge directly from Eastern cultural understandings of this concept.

Corresponding author: Bruno Martins
Address: Department of Integrative Clinical Nursing, University of Minho, Braga, Portugal.
E-mail: ✉ bruno.martins@gmail.com

Received: 16 May 2025; **Accepted:** 07 September 2025; **Published:** 20 December 2025

How to Cite This Article: Martins B, Pereira L, Azevedo R, Costa P. Psychometric Validation of the LED Good Death Index in Patients with Terminal Cancer: A Mixed-Methods Study. J Integr Nurs Palliat Care. 2025;6(1):232-41. https://doi.org/10.51847/b1eSolgmA7

Meier and colleagues performed a systematic examination of prior qualitative and quantitative studies. They distilled several fundamental themes, including desired characteristics of the dying process, the absence of pain, emotional stability, family involvement, preservation of dignity, a sense of life completion, spiritual or religious dimensions, choices about treatment, overall quality of life, and the nature of interactions with medical staff [7].

A different comprehensive review of the literature, which incorporated views from people who were dying, healthy individuals, and care professionals, uncovered four recurring themes: (1) good death viewed as a form of control, (2) the misguided good death, (3) the good death under threat, and (4) outright rejection of the reality of dying. According to Cotterell and Duggleby (2016), discussions of a "good death" frequently carry a negative tone because they are seen as attempts to manage or regulate the dying experience for both the person facing death and those responsible for providing care [8]. Across many East Asian cultures, serious illness and death have historically been regarded as unlucky or taboo subjects, causing most people to steer clear of any conversation about "death" [9]. Clinical practice has repeatedly revealed that what patients themselves hope for in a good death often differs from the expectations of their relatives and medical team. This mismatch prompted the research group to explore the topic through patients' eyes. Views on what makes a death good can shift dramatically depending on who is asked. Still, medical ethics places the highest value on patient autonomy, meaning the dying person's thoughts and wishes must be given top priority. Each individual holds both the right and the duty to define a good death on their own terms. For this reason, patients should be empowered to make fully informed, autonomous decisions about accepting or declining medical treatments. Such autonomy can significantly improve their quality of life and help them prepare for death in a way that aligns with their personal idea of a good death.

Assessing whether a patient is moving toward a good death is a fundamental part of quality palliative care. Over time, various scales and inventories have been developed in East Asian countries to measure the quality of death. A well-known example is the Good Death Inventory (GDI) from Japan, which comprises 18 domains and 54 items [10, 11]. These domains are split into 10 core areas and 8 optional ones. The 10 core domains include (1) environmental comfort, (2) life completion, (3) dying in a favorite place, (4) maintaining hope and pleasure, (5) independence, (6) physical and psychological comfort, (7) good relationships with medical staff, (8) not being a burden to others, (9) good relationships with family, and (10) being respected as an individual. The eight optional domains cover (11) religious and spiritual comfort, (12) receiving sufficient treatment, (13) control over the future, (14) feeling that one's life is worth living, (15) unawareness of death, (16) pride and beauty, (17) natural death, and (18) preparedness for death. Because it has 54 separate items, the GDI allows families to provide rich, detailed feedback on whether they feel the deceased person experienced a good death.

The development of the GDI relied on qualitative input from hospice nurses, a small-scale study of patients with advanced cancer, and observational data from patient settings. It has become a standard tool in palliative care research and everyday clinical work, always from the viewpoint of bereaved family members [12, 13]. In 2008, Miyashita reported that the GDI had good concurrent validity when compared with the Care Evaluation Scale and general care satisfaction scores. It also displayed solid internal consistency (alpha = 0.74–0.95) and reasonable test-retest reliability (ICC = 0.38–0.72) [10]. In parallel, the Good Death Score (GDS) was developed in Taiwan based on input from experts and university professors and is typically scored by palliative care staff [14]. The GDS is likewise used in both research and clinical palliative settings [15, 16]. Even so, while these regionally developed tools are widely in circulation, they have seldom been tested or validated through direct patient feedback.

A thorough review of the available literature shows that nearly all current good-death assessment instruments are filled out either by family members or by healthcare professionals. Instruments that let patients rate their own experience are almost nonexistent [17]. Although patient autonomy is universally upheld by medical professionals as a core ethical value, in East Asian settings, the autonomy of terminally ill patients is frequently overshadowed by family expectations and the traditional authority of physicians, largely because of deep-rooted Confucian values and the practice of filial piety [18]. Given the large population of terminal patients in East Asia, there is a genuine need for a culturally grounded psychometric instrument—built on Confucian principles and centered on genuine patient autonomy—that allows patients to evaluate their own dying process. Such a tool would benefit both day-to-day clinical care and future research.

The LED Good Death framework was constructed through extensive in-depth interviews with patients who had terminal cancer, followed by careful qualitative analysis carried out by a team of experts. This work was conducted within a research initiative funded by the Taiwan Ministry of Science and Technology [19]. LED is an acronym derived from the first letters of its three central themes: living in dying, experiencing the existential self, and dying in living [19]. Put simply, even when death is very close, people with terminal illness still need to affirm the value of their life and stay engaged with the present to reach a good death. This outlook echoes traditional Confucian thought, which stresses the importance of understanding life before death, as Confucius himself expressed: "Without knowing life, how can we know death" [20].

The purpose of this study was to provide healthcare teams with a practical scale that terminal patients can complete independently. This would give staff clearer insight into how patients feel about death and dying. In turn, caregivers would be better equipped to meet individual needs and guide patients with terminal illness toward achieving their own version of a good death.

Materials and Methods

Study design

This project was part of a larger 4-year research initiative supported by the Taiwan Ministry of Science and Technology and the Medical Research Department of MacKay Memorial Hospital. The main program was titled "Enhancing Medical Professionals' Knowledge and Skill to Good Death of Dying Patients and Normal Grief of Their Family." It ran from August 1, 2016, to July 31, 2020. Ethical clearance was obtained from the MacKay Memorial Hospital Human Research Ethics Review Board under reference number 15MMHIS113. Throughout the program, the Ministry of Science and Technology required annual progress reports documenting the research activities and results.

Data collection took place at the primary sites of MacKay Memorial Hospital, including the Taipei campus in Taipei City and the Tamsui campus in New Taipei City. MacKay Memorial Hospital is a major tertiary hospital with more than 2000 beds and offers full-spectrum cancer care as well as dedicated hospice and palliative services. Study participants were adult inpatients admitted to cancer wards or palliative care units, selected through purposive sampling. Every participant had to be at least 20 years old. Anyone under 20 or unable to read or write was excluded. Once informed consent was obtained, a research assistant assisted each participant in completing the questionnaire independently. The study was conducted in full accordance with the ethical principles of the Declaration of Helsinki.

Qualitative research method

In line with the qualitative work conducted by Fang *et al.* [19], the first stage of the qualitative phase involved recruiting 12 individuals diagnosed with terminal illness (life expectancy under 12 months) **(Table 1)** for semi-structured, in-depth interviews. Among them, 7 participants were female, and 4 were male. Their ages ranged from 29 to 73 years, with an average of 57.8 years. During the interviews, each patient answered five core questions: How would you characterize your daily life right now? What are your main thoughts and emotions about your present medical condition? What thoughts or feelings come to mind when you consider your impending death? In what ways would you like to use the time remaining to you? When you envision the actual moment of death, what kind of setting or atmosphere would you prefer? The latter part of each session was left open so patients could freely share any additional reflections. Before beginning, full consent was obtained to audio-record the conversations. Once completed, all recordings were transcribed verbatim and then processed using ATLAS.ti 7.5 software (Muhr T, ATLAS.ti Scientific Software Development, Berlin, Germany) with a hermeneutic phenomenological approach to analysis. To enhance the data's credibility, two external reviewers—a senior palliative medicine specialist and a social worker—were invited to provide triangulation by cross-checking the material and verifying the research team's interpretations. Following thorough analysis and validation, the findings revealed that patients living with terminal illness conceptualized their "good death" experiences through three main dimensions [19]. The first dimension, termed "living in dying (L)", contained five specific aspects: (1) establishing a life pattern, (2) recalling past times, (3) confirming self-identity, (4) connecting with essential others, and (5) maintaining a doctor-patient relationship. The second dimension, "experiencing the existential self (E)", included five aspects: (1) positive responses to sick experiences, (2) conflicting feelings at the border between life and death, (3) maintaining personal autonomy, (4) authentic companionship with others, and (5) settling in with religious or spiritual experiences. The third dimension, "dying in living (D)", comprised five aspects: (1) having a complete understanding of the disease, (2) facing death with a rational attitude, (3) being aware of death through physical conditions, (4) planning after death, and (5) anticipating the situation of death [19].

Table 1. Relevant information of the 12 interviewees

Participant ID	Gender	Age (years)	Marital status	Children (n)	Educational level	Employment status	Cancer diagnosis	Interview length
M1	Male	62	Separated	2	College	Resigned	Nasopharyngeal Cancer	90 min
F1	Female	73	Married	5	Elementary School	Retired	Breast Cancer	30 min
F2	Female	56	Married	1	Elementary School	Unemployed	Breast Cancer	40 min
F3	Female	63	Divorced	2	Elementary School	Retired	Colorectal Cancer	120 min
F4	Female	45	Single	0	College	Resigned	Colorectal Cancer	35 min

F5	Female	58	Married	2	College	Retired	Breast Cancer	75 min
F6	Female	65	Divorced	2	College	Retired	Lung Cancer	50 min
M2	Male	61	Married	1	High School	Retired	Lung Adenocarcinoma	60 min
M3	Male	29	Single	0	College	Resigned	Liver Cancer	50 min
M4	Male	59	Married	2	College	Employed	Pancreatic Cancer	45 min
M5	Male	63	Widowed	1	College	Retired	Lung Cancer	60 min
F7	Female	60	Married	0	College	Retired	Breast Cancer	90 min

Quantitative research method

The primary investigator, together with the co-investigator, developed 15 assessment items drawn directly from the 15 aspects identified in the qualitative phase, while also consulting supporting literature in the field. These 15 items were formatted on a four-point Likert-type scale where responses were scored as follows: 4 for “strongly agree”, 3 for “agree”, 2 for “disagree”, and 1 for “strongly disagree” (with total possible scores ranging from 15 to 60). The resulting instrument was designated the LED-Good Death Index (LED-GDI) **(Table 2)**. Higher scores on this index reflected a heightened perception of a good death. To evaluate content validity, seven specialists from pertinent disciplines participated in an expert panel review. The group consisted of two palliative care physicians, one psychiatrist focused on palliative care, one senior nursing supervisor, one social worker, and one experienced research assistant. Panel members reviewed each item for its relevance and clarity of expression. Following this, 30 patients were recruited to trial the LED-GDI and confirm that every statement was straightforward and comprehensible.

Table 2. Contents and rating of the LED-GDI

Item No.	Instruction: Please respond according to your current condition and personal feelings	Strongly disagree	Disagree	Agree	Strongly agree
1	I can remember positive experiences from my past.	1	2	3	4
2	I am capable of developing new ways of living.	1	2	3	4
3	I perceive my life as meaningful.	1	2	3	4
4	I can attain inner peace through religion or other approaches.	1	2	3	4
5	I can approach my illness with an optimistic outlook.	1	2	3	4
6	I can sustain strong relationships with people who matter to me.	1	2	3	4
7	I can cope with the challenges associated with treatment.	1	2	3	4
8	I maintain a positive relationship with my healthcare providers.	1	2	3	4
9	I can preserve my independence.	1	2	3	4
10	I experience supportive and caring interactions with others.	1	2	3	4
11	I am fully aware that my remaining time is limited.	1	2	3	4
12	I understand how to confront the end of life.	1	2	3	4
13	I recognize the limitation of my lifespan due to physical decline.	1	2	3	4
14	I have been able to organize my personal matters.	1	2	3	4
15	I can envision myself passing away peacefully.	1	2	3	4

All statistical analyses and descriptive summaries were executed using SPSS for Windows, version 18.0. Reliability checks and detailed item analyses were performed on the set of indicators. An independent-samples t-test was applied after dividing participants into high- and low-scoring groups to examine each item’s performance. Correlations were also computed between the mean score for each item and the total scale score. After these preliminary evaluations, an exploratory factor analysis (EFA) was conducted, using the Kaiser–Meyer–Olkin (KMO) measure and Bartlett’s test of sphericity to assess the appropriateness of factor extraction. Since the scale had originally been constructed from qualitative data and grouped into 15 items across three conceptual domains, the EFA results were used to reorganize the item sequence based on the observed statistical patterns. As a final step, confirmatory factor analysis (CFA) was conducted with AMOS software, version 24.

Results and Discussion

Demographic characteristics of the participants

The study successfully enrolled 144 patients. Participants had a mean age of 57.54 years (SD = 11.195), with 76 males and 68 females. In terms of religious background, 28 identified as Christian, 42 as Buddhist, 45 as Taoist, 5 as adherents of other faiths, and 23 reported no religious affiliation. Occupational backgrounds varied: seven were civil servants, 21 worked in industry, eight in commerce, 11 in service roles, 10 were self-employed, one was a student, 60 were retired, and 26 fell into miscellaneous categories. Education levels showed that 61 participants had completed junior high school or less, 45 had finished senior high school, and 36 held college-level qualifications or higher. The most frequent cancer types were malignancies of the upper digestive system and lower digestive system, each affecting 30 patients. The remaining cases included 19 patients with head and neck cancer, 18 with breast cancer, 17 with cancers involving the respiratory system, 16 with reproductive system cancers, and 14 with other cancer diagnoses **(Table 3)**.

Table 3. Demographic characteristics of the participants (n = 144)

Variable	Category	N (%)
Gender	Male	76 (52.8)
	Female	68 (47.2)
Religious affiliation	Christianity	28 (19.4)
	Buddhism	42 (29.2)
	Taoism	45 (31.3)
	Other religions	5 (3.5)
	No religious affiliation	23 (16)
Employment status	Government employees	7 (4.9)
	Industrial laborers	21 (14.6)
	Business sector workers	8 (5.6)
	Service industry workers	11 (7.6)
	Self-employed	10 (6.9)
	विद्यार्थी (Students)	1 (0.7)
	Retirees	60 (41.7)
	Other occupations	26 (18.1)
Educational attainment	Junior high school or below	61 (42.4)
	Senior high school	45 (31.3)
	College or higher education	36 (25)
Type of cancer	Head and neck cancers	19 (13.2)
	Respiratory cancers	17 (11.8)
	Breast cancer	18 (12.5)
	Upper gastrointestinal cancers	30 (20.8)
	Lower gastrointestinal cancers	30 (20.8)
	Reproductive system cancers	16 (11.1)
	Other cancer types	14 (9.7)
Hospital ward type	Palliative care wards	45 (31.3)
	Oncology wards	80 (55.5)
	General internal medicine wards	19 (13.2)

Item analysis

Item-level examination indicated that the LED-GDI produced an overall mean score of 49.43 (SD = 5.834). Among the individual items, the highest mean was recorded for Q8 ("I have a good relationship with the medical team") at 3.54 (SD = 0.527). This was followed closely by Q10 ("I can feel good interaction and caring with others") with a mean of 3.47 (SD = 0.566). The third strongest item was Q6 ("I can maintain good connections with individuals who are important to me"), scoring 3.45 (SD = 0.624) on average.

On the lower end, the three weakest items were Q2, Q3, and Q12. Q2 ("I can build new lifestyles") received a mean score of 3.08 (SD = 0.762). Q3 ("I feel that my life has value") averaged 3.15 (SD = 0.757). Q12 ("I know how to face the end of life") had a mean of 3.16 (SD = 0.799).

When participants were divided into high- and low-scoring groups, t-test results revealed statistically significant differences on every single item. Additional correlation analysis confirmed that each item was significantly associated with the total LED-GDI score **(Table 4)**.

Table 4. Item analysis of LED-GDI (n = 144)

Scale item	Item–total correlation	95% CI (Upper)	95% CI (Lower)	t-value	Kurtosis (SE)	Kurtosis (Stat.)	Skewness (SE)	Skewness (Stat.)	SD	Mean
Overall index score	—	—	—	—	—	—	—	—	5.834	49.43
Q1	0.550**	−0.639	−1.196	−6.538***	0.401	0.643	0.202	−0.855	0.778	3.17
Q2	0.606**	−0.830	−1.300	−9.009***	0.401	0.258	0.202	−0.623	0.762	3.08
Q3	0.622**	−0.833	−1.332	−8.627***	0.401	0.510	0.202	−0.741	0.757	3.15
Q4	0.607**	−0.662	−1.057	−8.664***	0.401	−0.598	0.202	−0.243	0.604	3.30
Q5	0.628**	−0.820	−1.145	−12.019***	0.401	0.290	0.202	−0.598	0.629	3.35
Q6	0.566**	−0.715	−1.085	−9.677***	0.401	1.715	0.202	−1.040	0.624	3.45
Q7	0.482**	−0.504	−0.907	−6.955***	0.401	1.542	0.202	−0.726	0.607	3.35
Q8	0.488**	−0.464	−0.813	−7.252***	0.401	−1.161	0.202	−0.459	0.527	3.54
Q9	0.584**	−0.768	−1.082	−11.674***	0.401	1.990	0.202	−0.915	0.637	3.33
Q10	0.616**	−0.597	−0.964	−8.448***	0.401	0.885	0.202	−0.709	0.566	3.47
Q11	0.530**	−0.700	−1.262	−6.932***	0.401	0.495	0.202	−0.949	0.836	3.19
Q12	0.518**	−0.653	−1.182	−6.891***	0.401	0.042	0.202	−0.713	0.799	3.16
Q13	0.695**	−0.771	−1.136	−10.384***	0.401	−0.609	0.202	−0.265	0.613	3.29
Q14	0.648**	−0.894	−1.237	−12.323***	0.403	0.720	0.203	−0.781	0.669	3.33
Q15	0.549**	−0.748	−1.183	−8.814***	0.401	0.896	0.202	−0.816	0.694	3.28

Notes: *** Correlation is significant at the 0.001 level (two-tailed). ** Correlation is significant at the 0.01 level (two-tailed).

Exploratory factor analysis and reliability

The preceding qualitative interviews had shown that terminal patients tended to understand and describe their “good death” experiences according to three core viewpoints: L, E, and D. In the current quantitative phase, the KMO statistic reached 0.805 and Bartlett’s test of sphericity was highly significant (P < 0.001), confirming that the dataset was appropriate for factor analytic procedures.

To preserve the original three-dimensional framework (L, E, and D) identified earlier, the principal component analysis used 3 factors. Although the qualitative findings initially assigned Q4–Q5 to the E dimension and Q6 and Q8 to the L dimension, the exploratory factor analysis prompted several adjustments to item grouping across the three factors **(Table 5)**.

Table 5. Rotated factors for principal components analysis of LED-GDI.

Scale items	Factor III	Factor II	Factor I
Factor 1: Living while dying (L)			
LED.Q1 Ability to remember meaningful past experiences			0.759
LED.Q2 Capacity to develop new ways of living			0.757
LED.Q3 Perception of life as meaningful			0.688
LED.Q4 Ability to achieve peace through religious or other approaches			0.580
LED.Q5 Ability to approach illness with a positive mindset			0.479
Factor 2: Experiencing the existential self (E)			
LED.Q7 Ability to cope with treatment-related challenges		0.686	
LED.Q9 Ability to preserve personal autonomy		0.678	
LED.Q8 Maintaining a good relationship with the healthcare team		0.671	
LED.Q6 Sustaining meaningful relationships with important individuals		0.559	
LED.Q10 Experiencing caring and supportive interactions with others		0.525	
Factor 3: Dying within living (D)			
LED.Q11 Awareness of limited remaining lifespan	0.853		
LED.Q13 Recognition of life limitation due to physical decline	0.840		
LED.Q12 Understanding how to confront end-of-life	0.683		
LED.Q15 Ability to envision a peaceful death	0.562		
LED.Q14 Ability to organize personal affairs	0.480		

Reliability testing yielded a Cronbach's alpha of 0.854 for the complete LED-GDI scale. The three subscales showed alphas of 0.766 for living in dying (L), 0.718 for experiencing the existential self (E), and 0.788 for dying in living (D). Furthermore, all three factors showed strong, significant correlations with the overall instrument score **(Table 6)**.

Table 6. Reliability of the LED-GDI (n = 144)

Scale component	Correlation with total score[a]	Cronbach's Alpha	SD	Mean score
Overall scale score	—	0.854	5.834	49.43
Factor 1: Living while dying (L)	0.819**	0.766	2.551	16.05
Factor 2: Experiencing the existential self (E)	0.800**	0.718	2.0.5	17.15
Factor 3: Dying within living (D)	0.796**	0.788	2.669	16.24

Confirmatory factor analysis for construct validity

Confirmatory factor analysis was conducted using structural equation modeling to assess the proposed three-factor structure—living in dying (L), experiencing the existential self (E), and dying in living (D)—and the model's overall fit. The tested model included all 15 items distributed across the three factors. Key fit indices were as follows: $\chi^2 = 208.701$, df = 87, $\chi^2/df = 2.399$, P = 0.000, GFI = 0.847, AGFI = 0.789, and RMSEA = 0.09. Taken together, these statistics supported the validity of the three-factor structure and indicated an acceptable level of fit for the entire LED-GDI model **(Figure 1)** [21-23].

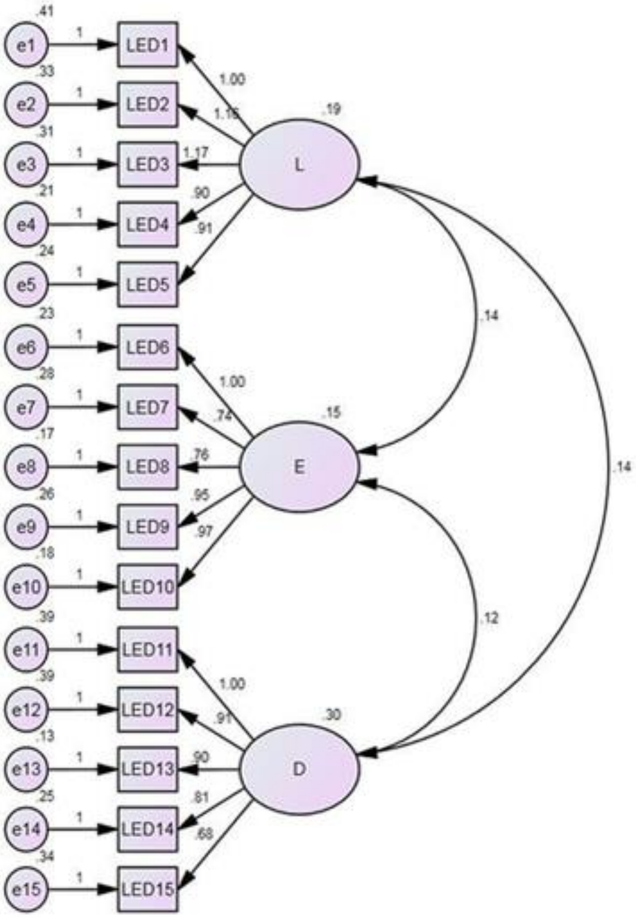

Figure 1. Confirmatory factor analysis of the three-factor model of the LED-GDI. (L) Living in dying, (E) Experiencing the existential self, (D) Dying in living.

This research appears to be the pioneering effort in developing an instrument that enables patients with terminal illness to directly evaluate their own progress toward a good death experience. Upon examining previous literature, the team observed that most existing scales depend on family members providing retrospective judgments about the quality of death once the patient has already died, instead of allowing the patients to report their personal perceptions while still alive [10, 16, 24, 25]. Taiwan introduced the Patient Autonomy Act in January 2019, establishing a new legal framework that grants patients greater control over their healthcare choices.

This change is especially meaningful because decisions such as declining futile interventions or opting for palliative support are now enshrined in enforceable legal rights [18]. In 1997, the Institute of Medicine described a good death as one “in which patients and their families are spared from suffering; their wishes are honored, within the context of clinical, cultural, and ethical considerations” [26].

According to Emanuel, patients often express deeper concerns about preserving dignity, avoiding excessive dependence, not becoming a burden to others, and retaining personal control compared with worries about physical pain or emotional distress [27]. Steinhauser similarly argued that addressing bodily needs is only the initial step; psychological, spiritual, and relational dimensions are equally important for both the patient and their loved ones [28]. A comprehensive “whole person” viewpoint is therefore necessary to fully appreciate the nature of suffering experienced by individuals at the end of life. In Taiwanese society, protecting personal dignity, facilitating a good death, helping families recognize the patient’s authentic preferences, and easing the sense of guilt or regret that survivors may feel are regarded as essential social obligations and fundamental expressions of human rights. The LED-GDI was created precisely to meet this need by offering patients a means to express their own expectations for a good death and enabling caregivers and families to gauge whether those expectations are being fulfilled.

The Good Death Inventory (GDI), originally developed by Japanese specialists in palliative medicine, remains a popular scale for assessing the quality of death [10]. It has been successfully adapted into Korean, Taiwanese, and Chinese versions, each demonstrating strong reliability and validity [16, 24, 25]. However, the GDI functions as a backward-looking measure completed by grieving family members to determine whether they believe the deceased had a good death [10, 11]. While useful for capturing family perspectives, it cannot reveal how the patient themselves felt about their dying process during the time they were receiving care. Relying on bereaved relatives’ views is consistent with longstanding Confucian traditions in East Asia, where direct conversations about death during serious illness are often avoided as culturally inappropriate [29, 30]. Nevertheless, contemporary clinical practice in end-of-life care is increasingly emphasizing the importance of hearing directly from patients about whether they sense they are approaching a good death, even within East Asian healthcare settings.

The scale developed by our team differs markedly from the GDI in both its design and its underlying philosophy. The LED-GDI emerged from in-depth conversations conducted directly with patients facing terminal illness and is structured around three primary domains. Its novelty lies not merely in being patient-completed but also in its distinct conceptual foundation that prioritizes continued meaningful living even in the final stages. Kübler-Ross [31] famously asserted that “the dying is, in fact, living,” reminding us that individuals with terminal conditions, although constantly aware of impending death, must still decide how to live their remaining time. For this reason, the first domain is labeled “living in dying” (L), acknowledging that patients continue to engage fully with life’s moments as long as they are alive. The second domain focuses on “experiencing the existential self” (E). Because patients remain alive while simultaneously confronting the reality of their approaching end, the third domain is termed “dying in living” (D) [18].

Three ideas expressed by Confucius in the Analects, recorded over 2400 years ago, closely align with the understanding of a good death uncovered in this study. The first states: “If you do not understand life, how can you understand death?” — underscoring Confucianism’s primary concern with how to live meaningfully. The second observes: “Life is lighter than a feather, and death is heavier than Mount Tai,” suggesting that a purposeful death carries greater weight than an aimless life. The third notes: “If you hear the Dao (truth) in the morning, you can die in the evening,” reflecting the belief that the search for life’s truths should persist until the very end [20]. These classical teachings are clearly embodied in the LED-GDI’s philosophical approach. To promote excellent care and support patients in reaching a good death, the mean total score on the LED-GDI in this sample was 49.43 ± 5.834. We therefore advise clinical teams to pay closer attention to any patient whose total score falls below 49, as lower scores may signal underlying distress contributing to existential suffering.

The study has several limitations. First, the development of the LED-GDI as a self-assessment tool for good death did not include comparisons with other established measures, such as quality-of-life instruments. As a result, it illuminates patients’ subjective sense of approaching a good death but does not address broader end-of-life concerns. Second, data collection occurred within a single hospital, which may have produced a relatively uniform pattern of end-of-life care practices. Third, the sample was restricted to patients with terminal cancer, leaving open the question of whether the LED-GDI would be suitable for individuals with other terminal conditions.

Subsequent research should strive to assess the concept of a good death concurrently from the perspectives of patients, family members, and healthcare providers to strengthen comprehensive end-of-life support. Additional validation is needed to establish whether the LED-GDI can function effectively as a good death measure for non-cancer terminal illnesses. We also encourage palliative care teams in other locations — particularly throughout East Asia — to trial the LED-GDI and explore its value in helping determine whether patients are progressing toward a good death.

Conclusion

The LED-GDI is an assessment instrument developed through direct patient interviews to help determine whether individuals feel they are attaining a good death. Its standout characteristic is the incorporation of existential ideas organized into three domains: L, E, and D. The scale has demonstrated acceptable reliability, suggesting that even patients with advanced cancer receiving palliative care can retain a meaningful awareness of their own existence. In the 21st century, particularly following the coronavirus disease 2019 pandemic, people have increasingly embraced a more self-directed outlook on both living and dying. Against this backdrop, the primary objective of clinical end-of-life care should be to ascertain whether patients with terminal illness can move toward a good death while continuing to live as fully as possible until their last moment.

Acknowledgments: We sincerely thank the patients with terminal cancer who participated in this study for expressing their opinions on a good death, even though they were facing death threats. We are grateful to three experts for their professional opinions: Dr. Chien-An Yao, head of the palliative care unit at National Taiwan University Hospital; Ms. Ching-Hui Chung, social worker and education lecturer at MacKay Hospice and Palliative Care Center; and RN. Chih-Ju Liu, nursing supervisor in cancer care units at MacKay Memorial Hospital.

Conflict of interest: None

Financial support: This study was supported by grants from the Taiwan Ministry of Science and Technology [MOST 105-2511-S-195-001-, MOST 106-2511-S-195-001-, and MOST 107-2511-H-195-001-] for 3 years and the Department of Medical Research at MacKay Memorial Hospital.

Ethics statement: None

References

1. Ellershaw J, Dewar S, Murphy D. Achieving a good death for all. BMJ. 2010;341:c4861.
2. Rainsford S, Phillips CB, Glasgow NJ, MacLeod RD, Wiles RB. The “safe death”: an ethnographic study exploring the perspectives of rural palliative care patients and family caregivers. Palliat Med. 2018;32(10):1575-83.
3. Char DF, Tom KS, Young GC, Murakami T, Ames R. A view of death and dying among the Chinese and Japanese. Hawaii Med J. 1996;55(12):286-90.
4. Hsu CY, O’Connor M, Lee S. Understandings of death and dying for people of Chinese origin. Death Stud. 2009;33(2):153-74.
5. Shin DW, Lee JE, Cho BL, Yoo SH, Kim SY, Yoo JH. End-of-life communication in Korean older adults: with focus on advance care planning and advance directives. Geriatr Gerontol Int. 2016;16(4):407-15.
6. Lei L, Gan Q, Gu C, Tan J, Luo Y. Life-and-death attitude and its formation process and end-of-life care expectations among the elderly under traditional Chinese culture: a qualitative study. J Transcult Nurs. 2022;33(1):57-64.
7. Meier EA, Gallegos JV, Thomas LPM, Depp CA, Irwin SA, Jeste DV. Defining a good death (successful dying): literature review and a call for research and public dialogue. Am J Geriatr Psychiatry. 2016;24(4):261-71.
8. Cottrell L, Duggleby W. The “good death”: an integrative literature review. Palliat Support Care. 2016;14(6):686-712.
9. Huang V, Fiocco AJ. Measuring perceived receipt of filial piety among Chinese middle-aged and older adults. J Cross Cult Gerontol. 2020;35(2):195-208.
10. Miyashita M, Morita T, Sato K, Hirai K, Shima Y, Uchitomi Y. Good death inventory: a measure for evaluating good death from the bereaved family member’s perspective. J Pain Symptom Manage. 2008;35(5):486-98.
11. Miyashita M, Morita T, Sato K, Hirai K, Shima Y, Uchitomi Y. Factors contributing to evaluation of a good death from the bereaved family member’s perspective. Psychooncology. 2008;17(6):612-20.
12. Igarashi N, Aoyama M, Masukawa K, Morita T, Kizawa Y, Tsuneto S, et al. Are cancer patients living alone more or less likely to achieve a good death? Two cross-sectional surveys of bereaved families. J Adv Nurs. 2021;77(9):3745-58.
13. Kim JY, Park BK. The most important aspects for a good death: perspectives from parents of children with cancer. Inquiry. 2021;58:469580211028580.
14. Tsai JS, Wu CH, Chiu TY, Hu WY, Chen CY. Fear of death and good death among the young and elderly with terminal cancers in Taiwan. J Pain Symptom Manage. 2005;29(4):344-51.
15. Yao CA, Hu WY, Lai YF, Cheng SY, Chen CY, Chiu TY. Does dying at home influence the good death of terminal cancer patients? J Pain Symptom Manage. 2007;34(5):497-504.

16. Cheng SY, Dy S, Fang PH, Chen CY, Chiu TY. Evaluation of inpatient multidisciplinary palliative care unit on terminally ill cancer patients from providers' perspectives: a propensity score analysis. Jpn J Clin Oncol. 2013;43(2):161-9.
17. Kupeli N, Candy B, Tamura-Rose G, Jones L, King M, Higginson IJ, et al. Tools measuring quality of death, dying, and care, completed after death: systematic review of psychometric properties. Patient. 2019;12(2):183-97.
18. Cheng SY, Lin CP, Chan HYL, Chan YH, Ng TW, Lam WM, et al. Advance care planning in Asian culture. Jpn J Clin Oncol. 2020;50(9):976-89.
19. Fang CK, Lin TH, Pi SH, Lee JH, Li PI. The cancer patients with terminal illness' perspectives on good death (article in Mandarin). Taiwan J Hosp Palliat Care. 2017;22(3):288-309.
20. Confucius. The Analects of Confucius. Tredition Classics; 2013.
21. Hair JF, Anderson RE, Tatham RL, Black WC. Multivariate Data Analysis. 5th ed. Prentice Hall; 1998.
22. Nixon SJ, Parsons OA. Cloninger's tridimensional theory of personality: construct validity in a sample of college students. Pers Individ Dif. 1989;10(12):1261-7.
23. Schreiber JB, Nora A, Stage FK, Barlow EA, King J. Reporting structural equation modeling and confirmatory factor analysis results: a review. J Educ Res. 2006;99(6):323-38.
24. Shin DW, Choi J, Miyashita M, Kizawa Y, Shirahige Y, Morita T, et al. Measuring comprehensive outcomes in palliative care: validation of the Korean version of the Good Death Inventory. J Pain Symptom Manage. 2011;42(4):632-42.
25. Zhao J, Wong FKY, You L, Tao H. Validation of the Chinese version of the good death inventory for evaluating end-of-life care from the perspective of the bereaved family. J Pain Symptom Manage. 2019;58(3):472-80.
26. Field M, Cassell C. Approaching death: improving care at the end of life. Washington (DC): National Academy Press; 1997.
27. Emanuel EJ, Emanuel LL. The promise of a good death. Lancet. 1998;351:SII21-9.
28. Steinhauser KE, Christakis NA, Clipp EC, McNeilly M, McIntyre L, Tulsky JA. Factors considered important at the end of life by patients, family, physicians, and other care providers. JAMA. 2000;284(19):2476-82.
29. Chan CS-C. Culture, state and varieties of capitalism: a comparative study of life insurance markets in Hong Kong and Taiwan. Br J Sociol. 2012;63(1):97-122.
30. Chow AYM, McEvoy J, Chan IKN, Borschel M, Yuen JHL, Lo JYM. Do men and women with intellectual disabilities understand death? J Intellect Disabil Res. 2017;61(12):1130-9.
31. Kübler-Ross E. On Death and Dying. New York: Macmillan; 1969.