

# **Death, Dying and Bereavement**

*Measuring What Matters in End-of-Life  
Care*

By

**Chun-Kai Fang**

**Death, Dying and Bereavement: Measuring What Matters in End-of-Life Care**

**By Chun-Kai Fang**

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## About the Author

**Chun-Kai Fang** is a psychiatrist, psycho-oncologist, and palliative care specialist based at MacKay Memorial Hospital in Taiwan. He is a Professor and has held senior clinical and institutional leadership roles in mental health, suicide prevention, and hospice and palliative care. He is one of the developers of the Context–Users–Providers (CUP) model and the principal developer of the Hospice-Focused Palliative Outcome Index (HFPOI), an assessment framework designed to integrate relational ethics into structured measurement.

His work in palliative care has involved sustained collaboration across the Asia-Pacific region, while his scholarship in psycho-oncology engages in ongoing international dialogue. His academic interests center on measurement ethics, institutional grief, demoralization, and transcultural palliative care, with particular attention to how healthcare systems can remain accountable to persons rather than merely to performance.

# Foreword

It is with great enthusiasm that I write this foreword for a book that stands as a testament to the power of interdisciplinary collaboration and transformative impact of the CUP (Context–Users–Providers) model in palliative and hospice care. This book, entitled *Death, Dying and Bereavement: Measuring what Matters in End-of-Life Care* focuses on developing a comprehensive approach to palliative care that integrates ethical considerations, cultural sensitivity, and effective measurement tools.

The CUP model was born out of a collaborative effort by a group of six experts from diverse professional backgrounds and countries, including North America, Singapore, and Taiwan when we congregated at the 30<sup>th</sup> meeting of the International Work Group on Death, Dying and Bereavement. As the leader of the *CUP Model: Grief and Bereavement Care in Palliative Care Settings* work group, I am thrilled to see its profound relevance not only in academic circles but also in practical applications, particularly in Taiwan.

## **The Evolutionary Journey of the CUP Model**

The development of the CUP model was an intellectually rigorous process that involved addressing gaps in palliative care delivery from diagnosis to bereavement care two years post-death. Through interdisciplinary collaboration, we brought together experts from management, nursing, psychiatry, and social work to create a framework that prioritizes patient and family care ethically while respecting cultural and systemic nuances. One pivotal moment in the model's evolution was the recognition that effective palliative care cannot be delivered in isolation; it must account for the dynamic

interplay between institutional context, patient and family needs, and professional provider capabilities.

Our discussions highlighted the importance of “goodness-of-fit”, and the CUP model was designed to evolve, not as a static framework but as a living document that responds to changing realities. This iterative process ensured that the model would remain relevant across diverse settings, ultimately positioning it as a tool capable of transcending cultural and geographic boundaries.

## **Global Relevance**

While the CUP model was initially developed in response to unique challenges faced by its creators, its applicability extends far beyond these contexts. The framework's emphasis on integrating systemic structures, user values, and provider capacities makes it feasibly a universal tool for addressing the complexities of palliative care delivery, including its grief and bereavement care. The model's adaptability is further illustrated through case studies from other countries presented in the book. The examples demonstrate that the CUP model is not a one-size-fits-all solution but rather a conceptual framework that can be tailored to meet the needs of diverse populations.

## **Charting the Future: Evolution in a Changing Landscape**

As we look to the future, the CUP model may have the potential to evolve alongside technological advancements and shifting cultural attitudes toward palliative care. The integration of artificial intelligence (AI) into healthcare presents both opportunities and challenges. On one hand, AI can enhance decision-making by providing data-driven insights; on the other, there is a risk of algorithmic bias and the erosion of relational ethics.

The CUP model's emphasis on balancing systemic structures with human values will be crucial in navigating this changing landscape.

As this book delves into its applications, challenges, and future directions, I encourage readers to view it not as an endpoint but as a starting point for continued innovation and growth—grounded by our commitment to a framework that integrates both universal ethical principles and local sociocultural realities, providing a roadmap for ethical palliative care, grief and bereavement care practices.

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Associate Professor

Head, Department of Social Work  
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# Preface

This book did not begin with certainty. It began with unease.

Over the years, I have worked across psychiatry, palliative care, suicide prevention, institutional leadership, and professional governance. In clinical practice, I encountered the intimate realities of grief, demoralization, and existential distress. In administrative and policy-facing roles, I confronted a different landscape shaped by indicators, accreditation systems, benchmarking, and funding requirements. Both domains were necessary. Yet they did not easily speak to one another.

Theories of grief and bereavement have long enriched therapeutic understanding. They illuminate the inner processes of loss and guide individual intervention. However, they rarely address a structural question. How does an institution hold grief? How does a healthcare organization sustain compassion without reducing it to procedure? How does measurement, once embedded in governance and financing, alter what is recognized as suffering?

In 2018, during a working group at the International Work Group on Death, Dying, and Bereavement, these questions became unavoidable. Together with Geok Ling Lee, Jim Monahan, Gilbert Fan, Wai Yee Chee, and Christy Whitney, I participated in sustained discussion on grief and bereavement care within palliative institutions. The conversation did not seek novelty. It revealed a conceptual gap. Established grief theories offered depth for individual counselling but provided limited guidance for organizational design. What became increasingly clear was that institutions lacked a language for grief at the level of governance. We had models for therapy, but not for systems. We could describe suffering, but not how institutional

structures should respond to it. The challenge before us was not only therapeutic. It was institutional.

Conversations within the Asia Pacific Hospice Palliative Care Network, including exchanges with colleagues engaged in institutional and policy leadership across different health systems, further clarified this tension. Similar structural dilemmas repeatedly surfaced. Institutions sought accountability and comparability, while clinicians and families sought relational presence and moral coherence. These encounters confirmed that the challenge was not local but shared.

The Context–Users–Providers model emerged from this extended reflection. It was not conceived as a proprietary framework or as a comprehensive solution. It was an attempt to articulate how grief care might be understood simultaneously at the levels of context, users, and providers. It sought to bridge individual experience and institutional responsibility.

Only later, through years of clinical application and institutional refinement, did the Hospice-Focused Palliative Outcome Index take form. HFPOI was not the original aim of inquiry. It developed gradually as an effort to operationalize the ethical commitments embedded in CUP in response to practical demands for structured assessment. The framework preceded the instrument, and the ethical question preceded the metric. This sequence matters.

I write as someone situated within the systems I examine. My roles in clinical leadership and policy consultation have brought me close to the structures that shape how care is evaluated and funded. This proximity offers insight, but it also imposes limitation. The frameworks described here were developed within specific cultural

and institutional contexts. Their relevance elsewhere depends on adaptation, dialogue, and continued scrutiny.

The purpose of this book is not to reject measurement, nor to elevate any single framework above others. It is to ask what happens when measurement becomes governance, and whether structured assessment can remain accountable to relational ethics. In palliative care, to measure is to signal value. To design indicators is to shape institutional memory. To institutionalize frameworks is to influence how persons are seen at the threshold of death.

If this book contributes anything, I hope it contributes disciplined reflection. Structure must not eclipse relationship. Accountability must not silence dignity. Outcome measurement, however refined, remains ethically contingent. Institutions do not simply record care; they define it.

This work is not an endpoint. It is an invitation to sustained cross-cultural dialogue on how institutions might hold grief without diminishing it.

Chun-Kai Fang, MD, MSc, PhD

## **Part I – Rethinking Ethics in Palliative Care**

Chapter 1. The Crisis of Outcome Measurement in End-of-Life Care

Chapter 2. Ethical Foundations for Whole-Person Assessment

Chapter 3. Cultural Dimensions of Dying Well: An East Asian Perspective

# Chapter 1

## The Crisis of Outcome Measurement in End-of-Life Care

*For what shall it profit a man, if he shall gain the whole world, and lose his own soul?*

Mark 8:36, The Bible, King James Version

*It is no measure of health to be well adjusted to a profoundly sick society.*

Jiddu Krishnamurti (1895-1986), India

*You matter because you are you, and you matter to the end of your life.*

Dame Cicely Saunders (1918-2005), UK

### **1.1 Introduction: When Measurement Misses the Soul**

In modern palliative care, efforts to standardize “quality” often rely on quantifiable indicators: symptom control, survival length, and institutional metrics. These measures are indispensable for system-wide accountability, funding justification, and policy comparison. Yet a deeper question persists beneath their usefulness: what happens when the act of measuring begins to define what is worth valuing?

The crisis of outcome measurement in end-of-life care is not merely methodological; it is moral. When quality is equated primarily with what can be counted, dimensions such as dignity, relational integrity, spiritual peace, and existential completion risk becoming secondary, not because they are unimportant but because they resist

quantification. What is most human at the end of life is often what is least measurable.

A growing body of literature has challenged this overreliance on biomedical metrics. Mayland et al. (2022) note that many tools assessing end-of-life care for children and young people struggle to address spiritual and existential needs. Similarly, Tang et al. (2009) found that family caregivers often value relational and emotional dimensions more than physical indicators, yet such aspects are poorly reflected in most assessment instruments. Tang, Aaronson, and Forbes (2004) found that spirituality, social support, and living with a caregiver were key predictors of quality of life in hospice patients, highlighting that non-medical factors play a central role in well-being at the end of life.

This critique is not limited to non-Western settings. In a seminal qualitative study, Steinhauer et al. (2000) found that patients, families, and healthcare providers identified factors such as being treated as a person, achieving a sense of completion, having control, and affirming spiritual beliefs as central to a good death. These priorities often remain unmeasured in conventional tools, despite their importance to those most directly affected. The study revealed a disjunction between institutional metrics and the lived experiences of dying individuals and their caregivers—a gap not of data, but of moral orientation.

Even when validated, tools developed in Western contexts may inadequately reflect culturally embedded values elsewhere. In East Asian settings, the dying process is often understood not merely as a clinical trajectory but as the culmination of moral, familial, and spiritual life. Death is not simply a biomedical endpoint; it is a relational and ethical completion.

One ancient Chinese framework offers a compelling counterpoint. The Five Blessings (五福), recorded in *The Shoo King* or *The Book of Historical Documents* (6th century BCE), outline the ideal life through five aspirations:

1. Longevity (壽)
2. Wealth (富)
3. Health and peace (康寧)
4. Virtuous morality (修好德)
5. Peaceful death (考終命)

The final blessing of a peaceful death is regarded not as medical success but as moral fulfillment. To die naturally and with dignity is seen as the completion of an ethical arc. Within this perspective, death is not treated as an adversary to be endlessly delayed but as a meaningful conclusion woven into a life shaped by relationship and virtue.

Such a perspective invites a profound reexamination of how palliative outcomes are defined. If a good death is moral completion rather than biological endurance, then measurement cannot begin and end with the body. It must ask different questions. Instead of starting with symptom reduction alone, what if we began with dignity? Instead of focusing solely on the patient as an isolated individual, what if we evaluated the whole person within their relational and cultural world?

This chapter therefore initiates a critical reflection on the limitations of prevailing outcome metrics in palliative care. It argues that measurement is never neutral: it encodes values, shapes institutional behavior, and influences how suffering is recognized. Drawing on examples from Taiwan and broader Asia-Pacific settings, we begin a

journey toward frameworks that do not abandon accountability, but re-anchor it in whole-person ethics.

To measure what matters, we must first clarify what we believe truly matters.

## **1.2 The Rise of Quantification: How Metrics Became Dominant**

In the evolution of palliative care, the pursuit of standardized quality assessment has led to an explosion of metrics. From quality-of-life (QOL) indices to patient-reported outcome measures (PROMs), and further to structured tools like the Palliative Care Outcome Scale (POS) and Australia's Palliative Care Outcomes Collaboration (PCOC), these instruments have been promoted as evidence-based solutions to evaluate care effectiveness, ensure accountability, and inform health policies.

Currow et al. (2016) trace the historical development of national-level quality data systems, emphasizing the feasibility and desirability of voluntarily collecting outcome data to enhance palliative services. The authors argue that tools like PCOC emerged in response to both ethical and administrative demands. Their purpose is to make suffering visible, identify gaps in care, and provide justification for funding.

While both POS and PCOC were designed to improve quality and consistency in palliative care assessment, their foundational intents and real-world applications diverge in meaningful ways (Table 1.1). POS emerged from a psycho-social and patient-centered concern in the UK context, while PCOC developed as a national policy instrument in Australia, integrating multiple tools into routine clinical workflows. The comparison below highlights the structural

differences and shared tensions between the two, including questions around cultural fit, ethical utility, and clinical burden.

**Table 1.1** Comparative Overview of POS and PCOC

Category	POS (Palliative Care Outcome Scale)	PCOC (Palliative Care Outcomes Collaboration)
Origin and Institution	Developed in 1999 at King's College London, led by Prof. Irene Higginson	Initiated in 2005 by the University of Wollongong, Australia
Primary Aim	To assess patients' and families' subjective experiences during palliative care	To build a national database for quality monitoring and outcome comparison
Tool Composition	10 items covering symptoms, psychological needs, family distress, information needs	Five core tools (e.g., Symptom Assessment Scale, Palliative Care Phase)
Frequency of Use	Weekly or as needed	At each phase change—high frequency (almost daily)
Level of Application	Usable at both individual case and research levels	Primarily for institutional quality monitoring and policy purposes
Strengths	Simple structure, patient-centered, cross-culturally adaptable	Systematic standardization, comparability, real-time monitoring
Challenges and Limitations	Limited reflection of spirituality and cultural aspects; needs better adaptation for Asian settings	High assessment frequency burdens staff; may promote "checkbox care"

While structured tools have expanded the reach of outcome data in clinical settings, the ethical and practical implications of using quality of life (QOL) measures remain underexplored. Higginson and Carr (2001) argue that although QOL measures offer critical insights beyond biomedical data, such as relational support, psychological well-being, and existential concerns, they are often underutilized or misapplied in routine care. They caution that standardized QOL tools can risk reducing personhood to data points, especially when staff view them as substitutes for meaningful communication.

Moreover, the act of measuring QOL may create expectations that clinicians can resolve all aspects identified, although in reality issues such as loneliness or lack of meaning may lie outside the traditional remit of medical care. Critics have even labeled this trend as “overmedicalization” of life (Higginson & Carr, 2001), raising ethical questions about whether clinicians should intervene in every domain that a QOL tool reveals.

However, the widespread adoption of such tools is not without complications. Bolzani et al. (2023) compared paper-based and electronic versions of integrated palliative care instruments and revealed challenges in achieving measurement equivalence across platforms. Furthermore, the routine use of standardized metrics has raised concerns about ‘checkbox care,’ in which clinicians feel pressured to complete assessments even if the tools do not align with the patient’s actual experience.

While these instruments offer logistical utility, enabling benchmarking, research comparability, and systemic audits, they may also contribute to ‘measurement fatigue’ in clinical settings. For example, POS has been criticized for underrepresenting spiritual pain, and PCOC’s high-frequency reporting has been associated with staff burnout, particularly among nurses. These real-world constraints

underscore the need to balance structure with empathy, and data with meaning.

As this chapter unfolds, we explore how the rise of quantification, while well-intentioned, may obscure rather than illuminate the lived experiences of patients and caregivers.

The growing dominance of outcome measurement has undeniably advanced accountability and comparability in palliative care. Yet, as metrics multiply, they also risk becoming ends in themselves. The increasing sophistication of measurement has now culminated in the World Health Organization's 2021 *House of Palliative Care* framework, which, for the first time, has enabled a systematic global ranking of national palliative care development. This milestone invites reflection: when the world finally measures palliative care comprehensively, what exactly do we choose to count, and what might remain invisible?

### **1.3 Global Benchmarking and the Meaning of Measurement**

For the first time in the history of palliative care, the *Journal of Pain and Symptom Management* published a global ranking grounded in the **World Health Organization (WHO) 2021 framework for palliative care development** (Tripodoro et al., 2025). Conducted by the ATLANTES Global Observatory at the University of Navarra, the study assessed **201 countries** through fourteen standardized indicators, producing a **Global Development Score (GDS)** that classifies nations into four levels, including Emerging, Progressing, Established, and Advanced. This initiative marks a methodological and ethical shift: from fragmented mapping toward an accountable, comparable global system of measurement.

The WHO "House of Palliative Care" framework is built upon six interdependent domains, including community empowerment,

health policies, research, essential medicines, education and training, and integrated service delivery. These form a multidimensional vision of what health systems should value when ensuring the relief of serious health-related suffering. Unlike previous atlases that relied primarily on expert opinion, the 2025 study operationalized these indicators into a structured survey and validation process involving more than 440 accredited national experts. As Garralda and colleagues (2023) emphasized in their *Journal of Palliative Medicine* article, the ATLANTES Observatory functions not only as a data repository but also as an **active platform for engaging policymakers, professionals, and civil society**, a bridge between evidence and ethical action.

The results of the 2025 world map are striking. **Only 14 percent of countries achieved the Advanced level**, while **40 percent remain at the Emerging stage**, home to more than half of the global population. Even in high-income settings, the domains of **essential medicines and professional education** remain underdeveloped, revealing that structural inequity is not limited to economic constraints (Table 1.2). Yet there are bright examples: Thailand, Uganda, Chile, and Uruguay reached Advanced levels despite limited resources, demonstrating how political will, community advocacy, and moral commitment can transcend material barriers (Tripodoro et al., 2025).

**Table 1.2** WHO 2021 Framework and 14 Indicators at a Glance

(Source: Tripodoro et al., 2025; Garralda et al., 2023)

Domain (6)	Indicators (14)	Essence of Progress
<b>Community Empowerment</b>	1 Patient and caregiver advocacy groups	Civic and familial participation in care rights and dialogue.
	2 Advance care planning / end-of-life decision policy	
<b>Health Policies</b>	3 National plan or strategy	Institutional commitment and governance.
	4 Integration into primary health care	
	5 Dedicated unit in Ministry	

Domain (6)	Indicators (14)	Essence of Progress
<b>Research</b>	of Health 6 National scientific congresses 7 Peer-reviewed publications	Evidence generation and knowledge dissemination.
	8 Opioid consumption	
<b>Essential Medicines</b>	9 Availability of essential drugs 10 Access to immediate-release morphine	Equitable pain relief and clinical accessibility.
	11 Undergraduate	
<b>Education &amp; Training</b>	curriculum coverage 12 Specialist training programs 13 Adult specialized	Human-resource capacity and competence.
	services	
<b>Integrated Service Delivery</b>	14 Pediatric palliative care programs	Service coverage and population equity.

Each indicator is rated on a 1–4 scale (Emerging → Advanced); the mean of fourteen indicators constitutes the Global Development Score (GDS), reflecting the continuum of national maturity in providing integrated palliative care.

### Box 1.1

Three Take-Home Messages from 2025 (Synthesizing Tripodoro et al., 2025 and Garralda et al., 2023)

#### 1. Uneven Progress and Persistent Inequity

Most of the world still lacks comprehensive access to palliative care. Educational deficits and poor opioid availability remain the weakest global links.

#### 2. Policy and Professional Engagement as Catalysts

The ATLANTES expert survey found that **policymakers (5.6 / 7)** and **health professionals (4.4 / 7)** are the most influential drivers of

development. Dissemination through **regional atlases, social networks, and web-based tools** was viewed as essential for impact.

### 3. **Emerging Models of Hope**

Examples from **Thailand, Uganda, Chile, and Uruguay** show that moral conviction and community participation can generate system transformation even in resource-constrained contexts.

## 1.4 Ethical Blind Spots in Outcome Measurement

While the proliferation of outcome tools has brought rigor and comparability to palliative care, it has also introduced ethical dilemmas often overlooked in their implementation. At the heart of these challenges is a critical question: for whom are these measurements designed? And whose values are embedded in what is counted?

Many measurement frameworks emphasize clinical efficiency, policy benchmarking, and institutional accountability. However, as highlighted in the U.S. National Academies' report *Transforming End-of-Life Care* (2015), these goals can obscure the personal, spiritual, and relational aspects that patients and families deem most important. The overmedicalization of dying, without sufficient attention to cultural variation or existential dimensions, creates what may be termed as 'ethical blind spots.'

One such blind spot lies in the burden placed on patients, families, and providers to participate in repeated assessments. The promise of patient-reported outcomes presumes a level of cognitive, emotional, and temporal availability that many terminally ill patients simply do not possess. Pi, Fang et al. (2024), in their development of the LED-Good Death Index, noted that although patients are central to defining a good death, many have difficulty articulating or self-rating this experience, particularly in their final days. This raises a paradox: those

whose experiences we most wish to understand may be least able to report them.

Moreover, measurement burden is not confined to patients. Nurses and front-line staff often bear the practical workload of implementing tools such as PCOC, leading to burnout, detachment, and 'checkbox care.' When tools become ends in themselves rather than means of enhancing care, ethical misalignment occurs between the goals of the system and the needs of those within it.

Cultural variation further complicates these dynamics. In a 2022 cross-national study, Finkelstein et al. surveyed over 180 palliative care experts from 81 countries to evaluate how end-of-life care was perceived and delivered. Taiwan, the UK, and South Korea scored highest, yet stark disparities were found between high-income and low-income countries. While global standards offer a unifying language, they risk privileging values from resource-rich settings while overlooking localized understandings of dignity, death, and care.

Importantly, the study identified 13 key indicators of a good death, spanning clinical, emotional, and spiritual domains. While comprehensive, these indicators still warrant ethical scrutiny. Are they truly universal, or culturally contingent? Can they account for patients who choose silence, families who resist disclosure, or spiritual needs expressed outside formal religious language?

To foster this ethical reflection, Table 1.3 below offers an interpretive summary of the 13 indicators, paired with the moral questions they provoke:

**Table 1.3** Ethical Reflections on the 13 Core Indicators of a Good Death (Finkelstein et al., 2022)

No.	Indicator	Core Domain	Ethical Reflection
1	Clean, safe, and comfortable care environment	Physical dignity	Beyond hygiene—how does the environment uphold one’s personhood?
2	Died at place of choice	Autonomy	When choices are unavailable, are patients truly free to choose?
3	Received appropriate life-prolonging treatments	Proportionality of care	Are treatments aligned with patient values, or institutional defaults?
4	Spiritual, religious, and cultural needs supported	Existential & cultural respect	Whose beliefs are centered—patient’s or provider’s?
5	Care well coordinated across providers	Continuity of care	Does system integration prevent fragmentation—or depersonalize care?
6	Pain and discomfort managed to desired levels	Symptom control	Are patient-reported preferences privileged over clinician judgment?
7	Help with emotional coping	Psychological support	Is emotional support tokenized or truly present?
8	Encouraged contact with friends and family	Relational integrity	Are family dynamics respected, especially in diverse or strained contexts?
9	Helped with non-medical concerns	Whole-person care	Do systems recognize practical, legal, or existential burdens

No.	Indicator	Core Domain	Ethical Reflection
10	Clear and timely information for decision-making	Informed consent	outside of health? Are patients overwhelmed, bypassed, or genuinely empowered?
11	Asked enough questions to understand patient's needs	Attentiveness	Is listening performative or grounded in ethical presence?
12	Treated with kindness and sympathy	Compassionate care	Is kindness institutionalized, or left to individual goodwill?
13	Costs were not a barrier to receiving appropriate care	Justice and access	How do economic disparities ethically constrain a "good death"?

These reflections emphasize that while standardized indicators can guide and improve care, they must be held up to ethical light. Outcome measurement should not merely serve systems, it should honor people, especially when they are most vulnerable.

## 1.5 Patients and Families as Moral Agents

In the evolution of hospice and palliative care, patients and their families are increasingly being acknowledged not only as recipients of care but as moral agents—individuals and communities capable of ethical reflection and decision-making. In contrast to traditional biomedical models that place professionals at the center of decision-making, this moral framework emphasizes autonomy, relational responsibility, and culturally grounded choices.

Recent ethical discourse has shifted attention to the critical role of both patients and families in shaping what constitutes a "good death." The

enactment of the Patient Right to Autonomy Act in Taiwan in 2019 underscores this shift. However, studies show that true patient-driven autonomy remains difficult to implement. A national population-based study by Chang et al. (2022) revealed that although 79% of terminally ill patients in Taiwan had advance directives (ADs), 95% were signed by caregivers, not the patients themselves. Furthermore, non-cancer patients, especially those with cardiovascular diseases, had significantly lower AD completion rates. This data underscores a structural gap between the legal promise of autonomy and the lived experiences of end-of-life decision-making.

The ethical concept of "who decides" is particularly salient in East Asia, where family-centered decision-making often supersedes individual autonomy. This tension reflects a deep cultural legacy shaped by Confucian values such as filial piety and intergenerational responsibility. In such contexts, moral agency becomes a relational process, negotiated among family members rather than asserted by the individual alone.

This philosophical divergence stands in contrast to Western liberal ideals, which emphasize autonomy as self-determination. In East Asia, ethical agency often emerges through familial dialogue and collective decision-making. Yet, modern legislative changes, such as Taiwan's Patient Right to Autonomy Act or Korea's Life-Sustaining Treatment Decisions Act, signal a growing recognition that patients themselves must have an authoritative voice in defining a good death. This normative shift does not erase cultural expectations, but rather creates a new ethical terrain in which tensions must be continually negotiated.

**Box 1.2****A Case from Taiwan: The Farmer and His Rice**

This case from Taiwan reveals the transformative power of culturally sensitive and autonomy-affirming palliative care.

An elderly farmer in his eighties, originally from southern Taiwan and diagnosed with terminal cancer, had been transferred to a northern hospital for care. For several days, he had remained silent—emotionally withdrawn and disengaged, even from his wife, who stayed by his side. His three adult children, all busy with work, were not present in the ward. According to the palliative care team, the family had been making all the decisions on his behalf, with little input from the patient himself.

That Wednesday morning, I visited the patient during a team teaching ward round. As both a psychiatrist and a palliative care physician, I was concerned not only with his medical needs but also with the quality of our team's communication and the respect for his autonomy. The team told me, "He hasn't spoken for days. He just keeps turning away. We're not sure if it's depression or just resignation." I sat beside him and, after a moment of silence, gently asked:

"What type of rice do you grow?"

His eyes brightened instantly. He straightened up. He began to speak—at first slowly, then with growing clarity and pride. He talked about Taiken 9, a fragrant, high-quality sushi rice that is difficult to grow but delicious to eat. "That's the rice I insisted on," he said. "The old lady prefers Taiken 11, it's sturdier and easier to manage. But I always believed good rice had to be earned." His words flowed, of soil, rain, harvests, and a lifetime of striving to grow rice that nourished not just bodies but dignity.

That one question, anchored in personal memory and cultural identity, rekindled his sense of self. For the first time, he re-entered the space as a person, not just a patient.

That afternoon, his three children returned to the hospital and were told by our social worker about their father's unexpected awakening. Moved by his clarity and conviction, they finally recognized the importance of honoring