The Controversial Case of Jahi McMath

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The Reality of a Suspected Brain-Dead Patient

By

Calixto Machado

Cambridge Scholars Publishing

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DEDICATION

This book is dedicated to the memory of my friend-brother, **Dr. Antonio Hernández Cantón (Ñiquito)**. From our earliest childhood in Jovellanos, where our families were closely united, through our years of study, marriage, and professional life, our paths remained inseparable. Life prepared us to share not only friendship but brotherhood, one that endured across distance and time.

Ñiquito was more than an extraordinary physician; he was a man of profound humanity, loyalty, and courage. Alongside his beloved Maria del Carmen, with whom he shared an exemplary love and partnership, he built a family rooted in devotion and accomplishment. Together with my eternal companion, Yazmina, we shared not only the joy of youth and courtship but also the journey of marriage, family life, and countless memories. These bonds between our wives and us strengthened our friendship and made it part of the very fabric of our lives.

His love for medicine was inseparable from his passion for people. He served with dedication in Cuba, later in Spain, always leaving behind institutions, patients, and colleagues who recognized his talent, generosity, and leadership. His courage in the face of illness and his dignity until the very end remain for me an enduring lesson in strength and humanity.

I also dedicate this book to my family, the center of my life and the source of my strength: to my beloved wife **Yazmina**, to my dear daughters **Yazminita. Yanin**, and **my son-in-law Mauricio**, and to my four grandchildren—**Mauricito, Kakito, Mathias, and Fabián**—whose love and vitality inspire me every day. Even our two faithful dog companions, **Mozart and Max**, are part of this circle of affection and joy that sustains me.

It is with gratitude, admiration, and deep affection that I dedicate this book both to the memory of my irreplaceable friend and to my beloved family, as a tribute to the ties of love, friendship, and devotion that give meaning to life.

—Calixto (Kaki) Machado
Havana, September 18, 2025

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PREFACE

When I was first invited to evaluate Jahi McMath in New Jersey, I travelled with the conviction that my role would be to confirm a diagnosis of brain death. After decades devoted to the study of brain death and disorders of consciousness, I believed I was entering a familiar, though tragic, territory. But what I encountered in Jahi's case transformed not only my understanding as a neurologist, but also my sense of medicine's limits at the threshold between life and death.

The first time I reviewed her MRI, EEG, and heart rate variability recordings, I was profoundly shaken. Instead of the silent, irreversible absence of function that I expected, I saw signals of preserved structure and residual activity that defied the established criteria. My initial reaction was disbelief, followed by the sobering recognition that I was facing something entirely new. Jahi did not fit the accepted categories of brain death, vegetative state, or minimally conscious state. Her responses, physiological reactivity, and capacity for interaction revealed a distinct condition—one that medicine had not yet described. I came to define this state as the "*Responsive Unawake Syndrome*," a novel disorder of consciousness.

The path that followed was not easy. For years, I confronted scepticism, resistance, and even professional isolation. My early manuscripts detailing Jahi's condition were rejected repeatedly by leading neurological journals in the United States and Europe. Some editors refused even to send the papers for peer review. It was only after persistent effort that I succeeded in publishing her data in less prominent journals, ensuring that her case could not be erased from the scientific record. These struggles deepened my conviction that medicine must remain open to evidence, even when it unsettles long-accepted dogmas. In fact, I was the first neurologist to conduct an anatomical and functional study of Jahi.

This book is therefore both an academic work and a personal testimony. It documents the unprecedented clinical evidence of Jahi McMath's condition and situates it within the broader debates on brain death and disorders of consciousness. At the same time, it reflects my journey as a physician: the shock of encountering unexpected findings, the burden of defending them against entrenched scepticism, and the responsibility of giving scientific voice to a patient whose condition could not be contained by existing categories.

Jahi McMath's story is not only a medical case but also a profound lesson in humility. It reminds us that medicine, despite its advances, does not possess all the answers and that the line between life and death is more complex than our definitions suggest. By sharing her case and proposing the concept of *Responsive Unawake Syndrome*, I hope to contribute to a more rigorous, transparent, and compassionate approach to the most consequential diagnosis physicians are ever called to make: the declaration of death itself.

The chapters that follow begin with Jahi's history, tracing the events that brought her case into the center of worldwide debate. From there, the book develops detailed clinical, pathophysiological, and ethical analyses to deepen our understanding of consciousness and to challenge us to reconsider how we define the end of life.

I write these pages with humility, gratitude, and the deep sense that Jahi's legacy will continue to shape medicine's understanding of death and consciousness for generations to come.

Dr. Calixto Machado (The Author)

FOREWORD

In this book, Dr. Calixto Machado tells the story of Jahi McMath, a young woman in Oakland, California, whose life was tragically shortened by a postoperative hemorrhage producing cardiopulmonary arrest. Following resuscitation, physicians declared her brain-dead, igniting a conflict with her family over discontinuing treatment. Her family insisted that her mechanical ventilator and other treatments be continued. With this aggressive treatment, her heartbeat, circulation, and visceral organ and endocrine functions continued for 4.5 years before she succumbed to a catastrophic intestinal illness.

McMath's case became the subject of a highly publicized debate over her precise medical condition and its appropriate treatment. Readers will learn about the testing she underwent during her ongoing treatment and the vexing medical, ethical, and legal issues raised by her case. Dr. Machado, a neurologist and brain death expert, **was the first brain death specialist to examine and test her**. One of his journal articles was the earliest to describe her case and its significance.

Brain death is the common term for death determination by showing the irreversible cessation of all functions of the brain, because of injury or illness. It is currently recognized by physicians and society as the medical and legal standard for determining death and is practiced worldwide. Yet despite this degree of consensus, it remains controversial in some quarters, with opponents citing conceptual or religious reasons for rejecting it. One active controversy concerns the accuracy of the bedside neurological examination in confirming the diagnosis. As Dr. Machado unravels and explains the many layers of this case, he shows that what has been accepted as the perfect clinical diagnostic accuracy of brain death may not always be so.

Although Jahi McMath's case is singular, it is of great importance and remains troubling, as Dr. Machado explains in detail. McMath's case has also been analyzed by others (see, D.A Shewmon and N. Salamon), but because of her family's desire to protect her privacy, there remains limited public information about the medical particulars of her case. Dr. Machado provides numerous additional details on original personal, clinical, and ancillary tests here, drawn from his own experience.

Dr. Machado has achieved international recognition as an expert in the determination of brain death. He has published numerous articles on the

topic and, since 1992, has sponsored a quadrennial conference in Havana on brain death and related topics that has attracted many brain death authorities. Some of the proceedings of his conferences have been published, including his 2004 conference, to which I contributed an article, which was published in volume 550 of *Advances in Experimental Medicine and Biology*.

Dr. Machado concludes that the Jahi McMath case is unique and, in retrospect, most likely represents a new and hitherto undescribed disorder of consciousness. Whether all readers will agree with this conclusion, after reading this book, all will clearly understand how her well-documented case disturbs the consensus over the accuracy of bedside testing for brain death by showing that, even when the examination is performed according to the highest accepted medical standards, it may not be 100% sensitive.

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CHAPTER 1

THE HISTORY OF JAHI MCMATH

Jahi McMath's case stands as a defining moment in the history of modern medicine's understanding of brain death, legal definitions of death, and the ethical tensions that arise when those determinations are contested. This chapter traces her story from the initial surgical complication through the formal diagnosis of brain death, the ensuing legal struggle, and her subsequent life in New Jersey. It concludes with her final hospitalization and death in 2018. This narrative draws upon clinical records, legal proceedings, and medical evaluations. It thoroughly and respectfully reconstructs her *sui generis* clinical condition, setting the stage for deeper analyses in subsequent chapters.

The case of Jahi McMath (JM) is widely recognized as one of the most significant and controversial examples in the reexamination of the medical, legal, and ethical standards surrounding brain death (Burkle & Pope, 2015; Burkle, Schipper, & Wijdicks, 2011). Jahi was a 13-year-old girl who suffered severe complications following routine surgery in California, was declared brain-dead, and subsequently became the center of a national debate when her family resisted the removal of life support. She ultimately lived another four and a half years in New Jersey, where she was legally recognized as alive. This chapter presents a comprehensive, chronological account of her case—from the initial surgical crisis to the declaration of brain death, legal transfer, reassessment of her condition, and her final medical decline—incorporating detailed clinical data, legal records, and expert observations, which began in September 2014 (Lewis, 2018a, 2018b; C. Machado, 2020, 2021; Calixto Machado, 2022; C. Machado, 2022, 2023; C. Machado, Estevez, DeFina, & Leisman, 2018; Shewmon, 2018a, 2018b; Shewmon & Salamon, 2021, 2022; Truog, 2018b).

Fig. 1-1 A visual metaphor for the challenging case of JM. The image of the young girl with a damaged, yet still present, brain captures the ambiguity and controversy that surrounded her condition, forcing a re-examination of the line between life and death in modern medicine.

Initial Surgical Complication and Brain Death/Death by Neurological Criteria (BD/DNC) Declaration

JM, a 13-year-old girl with a history of obesity-related obstructive sleep apnea, was admitted to the Children's Hospital of Oakland (CHO) on December 9, 2013, for elective upper airway surgery (Shewmon & Salamon, 2021). That same day, she underwent a complex procedure—adenotonsillectomy, uvulopalatopharyngoplasty, and submucous resection of the inferior turbinates. The operation itself was uneventful, and she was alert in the ICU postoperatively. However, within hours, she developed

copious oropharyngeal bleeding, which led to her aspirating blood and experiencing cardiorespiratory arrest around 00:30 on December 10. After approximately 10 minutes of CPR, spontaneous circulation returned. She required intubation and aggressive resuscitative efforts, including blood products and vasopressors. This arrest resulted in profound hypoxic-ischemic injury, evident from subsequent metabolic acidosis, pulmonary complications, and elevated lactate levels.

Neurologically, she deteriorated rapidly. Imaging by December 11 showed diffuse cerebral edema and signs of herniation, while serial neurological assessments documented absent brainstem reflexes and unresponsiveness. The first EEG on December 11 was isoelectric; however, the apnea test did not meet technical guidelines, with $PaCO_2$ rising only from 51 to 67 mmHg, which is below the 20-mmHg threshold specified in both pediatric and adult guidelines. Additionally, concerns were raised about residual drug effects and insufficient time off paralytics. Nevertheless, she was presumed to meet brain death criteria.

By December 12, a second neurological exam was conducted. This included a complete apnea test, where $PaCO_2$ rose from 33 to 70 mmHg with no respiratory effort. At that time, sedatives had been discontinued for over 36 hours, and Jahi exhibited flaccidity, areflexia, and persistent coma. She was formally declared brain dead at 15:00 that day (Winkfield v. Children's Hospital Oakland, 2014).

Over the next few days, despite being declared dead, her physiological condition prompted reflection. She developed diabetes insipidus, with managed electrolyte imbalances, intermittent fevers, and persistent vital signs. Her family opposed the withdrawal of support, requesting further evaluation and filing legal action to delay extubating. Despite continued medical deterioration due to lack of nutritional support, she remained hemodynamically stable enough to raise questions about the finality of her diagnosis. Further confirmatory tests—including three additional EEGs and a radionuclide cerebral blood flow study using Tc-99m—were also interpreted as supportive of brain death. However, Dr. D. Alan Shewmon later noted inconsistencies, such as autonomic fluctuations, temperature regulation, and hypertension without the use of pressors, which challenge the absolute cessation of hypothalamic and brainstem function. (Shewmon, 2018b; Shewmon & Salamon, 2021; Truog, 2018b)

Legal Dispute and Transfer to New Jersey

Following Jahi's declaration of brain death on December 12, 2013, her family initiated a legal battle to prevent the withdrawal of life support.

Despite the issuance of a California death certificate, her mother sought further evaluation and challenged the diagnosis in court. (Goodman, 2014) After several legal proceedings, a judge permitted her transfer to New Jersey—a state that allows religious objection to the neurological determination of death ("Winkfield vs. Children's Hospital Oakland", 2014).

On January 5, 2014, Jahi was transported to a hospital in New Jersey, where she was treated as a living patient. This legal and medical transition was historically unprecedented, resulting in two death certificates over four years apart. (C Machado et al., 2017; Truog, 2018a, 2018b)

Independent Medical Involvement

At the center of this controversial case, the International Brain Research Foundation (IBRF) invited Dr. Calixto Machado, an internationally recognized neurologist and expert in brain death and disorders of consciousness, to provide independent consultation regarding JM's condition. Recognizing the case's legal and clinical complexity, Dr. Machado recommended a comprehensive battery of electrophysiological and neuroimaging assessments. These were conducted both at Rutgers University Hospital in Newark, New Jersey, and at Jahi's residence in New Jersey. Dr. Machado personally analyzed multiple diagnostic studies, including MRI, MR angiogram, MR venogram, and serial EEGs. His evaluations offered unprecedented insight into Jahi's neurological status and challenged the prevailing diagnosis of brain death. Dr. Machado's findings suggested the presence of a previously undescribed disorder of consciousness, distinct from established categories such as BD/DNC or the minimally conscious state (C. Machado, 2020; C Machado et al., 2017).

A pivotal evaluation was conducted on September 26, 2014, under Dr. Machado's supervision, with MRI studies performed using sequences and slice parameters he had specified. Although a requested angio-CT was not authorized, the available data were sufficient for a detailed clinical reassessment. Upon returning from New Jersey, Dr. Machado compiled his observations and submitted a detailed manuscript summarizing the findings. Although initially rejected by numerous high-impact journals, the paper was ultimately published in *Functional Neurology, Rehabilitation, and Ergonomics* in 2016. This publication marked the first in-depth presentation of JM's anatomical and functional brain data (C Machado et al., 2017).

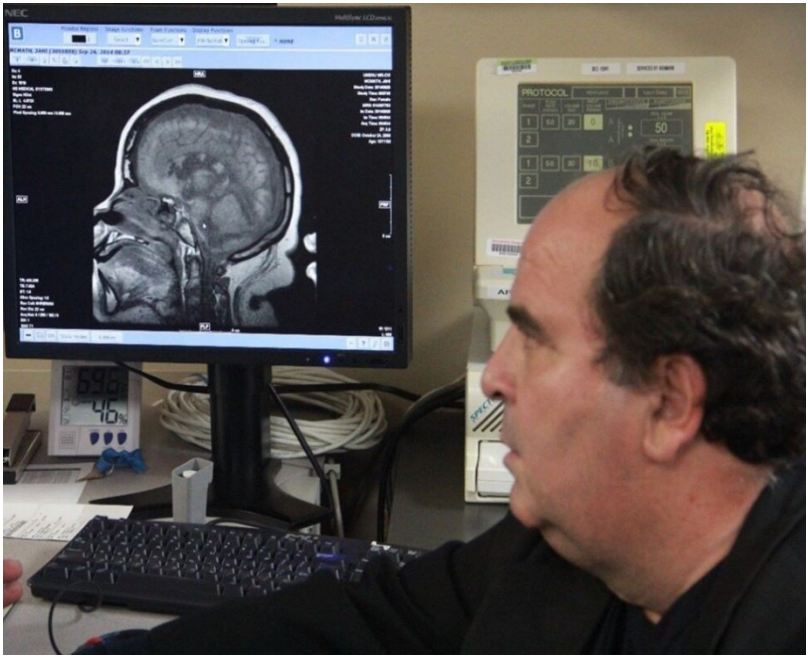

Fig. 1-2 Dr. Calixto Machado at RUH during the MRI study of JM. Dr. Machado's astonishment is evident as he reviews the T1 sagittal MRI (September 26, 2014).

During the "*50th Anniversary conference commemorating the Harvard Criteria for Brain Death*," Dr. D. Alan Shewmon referenced Dr. Machado's publication in a dedicated session on the McMath case. Dr. Shewmon included a slide from Dr. Machado's 2016 paper and highlighted its contribution to the discourse on disorders of consciousness. Shewmon, who independently evaluated Jahi's condition, analyzed videos provided by Nailah Winkfield. He concluded that Jahi's movements were purposeful and anatomically related to commands, indicating preserved cortical activity (Alexander, 2019; Shewmon, 2018a; Shewmon & Salamon, 2021). Findings on autonomic reactivity were consistent with these observations, reinforcing evidence that her condition transcended existing classifications of disorders of consciousness. (C. Machado, 2020)

At the VIII International Symposium on Brain Death and Disorders of Consciousness, held in Havana from December 4-7, 2018, the Author presented a lecture titled "Vegetative State (PVS-UWS), Minimally Conscious State, Brain Death, or a New State of Disorder of Consciousness?" This lecture summarized the findings on JM. At the same

conference, the Author also organized a round table discussion, "JM and Other Controversial Brain-Death Cases," which featured prominent leaders in the field (Figure 1-2).

Fig. 1-2 Round Table on "JM and Other Controversial Brain-Death Cases," featuring prominent leaders, presented at the VIII International Symposium on Brain Death and Disorders of Consciousness, held in Havana from December 4-7, 2018. (Photo from Dr. Machado's collection).

A Transformative Legacy

The case of JM represents a pivotal chapter in the ongoing examination of brain death and consciousness. Expert evaluations using advanced diagnostic tools—including neuroimaging, EEG analysis, and heart rate variability studies—provided compelling evidence of preserved intracranial structures, residual cognitive processing, and autonomic responses. These findings have broad implications for neurology and medicine and were the first objective clinical results, based on ancillary tests of JM's brain, published in a low-impact journal after being rejected by more than 10 neurological journals in the US and Europe.

This book, authored by Dr. Calixto Machado, presents the most detailed and systematic clinical and pathophysiological analysis of the JM case to date. It proposes a new conceptual framework for interpreting prolonged disorders of consciousness and highlights the need to reevaluate diagnostic criteria in complex medico-legal contexts. The following chapters will continue to elaborate on these findings.

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CHAPTER 2

THE EVOLVING DEFINITION OF DEATH: FROM ANCIENT BELIEFS TO NEUROCENTRIC CRITERIA

Introduction: The Evolving Concept of Death through History

Death, a universal human experience, has been understood and defined with remarkable fluidity across cultures and eras. Historically, its determination was primarily based on the cessation of easily observable vital signs, namely breathing and heartbeat. This seemingly straightforward definition, however, would be profoundly challenged by advancements in medical science and technology. This chapter traces the profound evolution of the concept of death, from ancient spiritual interpretations to the precise medical and technological definitions of the modern era. A particular emphasis will be placed on the pivotal advancements of the 19th and 20th centuries, which necessitated a fundamental re-evaluation of what it means to be alive or dead, ultimately leading to a paradigm shift from a cardiocentric to a neurocentric understanding of death (Pernick, 1988)

The journey towards a neurocentric understanding of death is a testament to scientific progress, specifically the development of tools that allowed physicians to peer deeper into the body's internal workings and sustain life artificially, thereby challenging traditional definitions and raising complex ethical questions. This evolution was not solely driven by technological progress. Still, it was deeply intertwined with evolving philosophical assumptions, notably the tension between mechanistic philosophy and vitalism, which shaped the conceptualization of life and death. The redefinition of death, therefore, is not merely a scientific or technological problem, but a deeply philosophical one, rooted in humanity's understanding of consciousness, life, and the integration of the body (J. L. Bernat, 2004; C. Machado, 1994, 1999, 2007b) (C. Machado, 2007a).

This complex, multi-faceted evolution sets a broader context for the report, demonstrating that the "paradigm shift" is less a discrete event and

more a series of conceptual and practical adjustments in response to new capabilities and understandings, emphasizing the dynamic nature of the definition of death. The modern difficulty in determining who is dead is not unprecedented; it is a recurring issue throughout medical history, often stemming from new medical discoveries, but always influenced by a complex interplay of social, professional, and ethical factors, as death has never been completely definable in objective, technical terms. (C. Machado, 2007a; Pernick, 1988)

In ancient times, the determination of death was largely based on simple observational techniques, grounded in visible signs of life—or their absence. Among the most common methods was placing a mirror or glass under the nostrils to observe for fogging, which would indicate the presence of breath. This practice was widespread and easily administered without any tools beyond what could be found in a household. Similarly, calling the person by name—often three times—was rooted in the belief that a living soul might respond to familiar auditory cues. If there was no response, the subject was presumed dead. These techniques, while rudimentary, reflected early attempts to distinguish living from the deceased in an era devoid of modern medical instruments. (Alexander, 1980; Ameri et al., 2020; Byard, 2023; Lizza, 1999a, 1999b, 2005)

Other physical tests complemented these methods. Feathers or candles were held near the nostrils to detect airflow; their stillness would signify no breathing. Some even placed bowls of water or oil on the chest to detect the gentle rise and fall caused by respiration. In more elaborate tests, the body might be submerged to see if air bubbles escaped from the lungs—a crude gauge of residual life. Instruments like hygrometers were occasionally employed, though their reliability was questionable.

Fig. 2-1 Ancient methods to diagnose death. Painting depicting ancient methods of diagnosing death, with figures gathered around a body holding a mirror and a bowl of water. (Figure created by the author using AI).

Shakespeare famously alluded to these methods in *King Lear* (Act 5, Scene 3), with the line, “If that her breath will mist or stain the stone, why then she lives,” capturing the dramatic poignancy of such a simple, yet vital test. These practices, however imprecise, laid the foundation for the evolution of more scientific criteria in death determination.

Fig. 2-2 William Shakespeare and his written work "*King Lear*." The portrait of Shakespeare is known as the "*Chandos portrait*." The artist may be John Taylor, a painter and an essential member of the Painter-Stainers' Company. Ancient Civilizations: Death as a Spiritual and Societal Transition (Pre-17th Century) "*This image is in the public domain; PD-ART, due to its age; PD-OLD-100*"). King Lear painting by George Frederick Bensell. The Knohl Collection.

In primitive and preliterate societies, death was a familiar and often rapid experience, mainly due to rudimentary medical practices and inadequate defences against predators. Attitudes toward death varied significantly, ranging from profound fear, rooted in the belief that death was an unnatural, accidental occurrence, to a more accepting view that perceived death not as an end but as a change in existence where the soul transitioned to another realm. These diverse beliefs were often accompanied by various pre-death rituals and elaborate funeral practices, designed either to honor the deceased or to mitigate fears about their potential malevolence toward the living (Lizza, 1999a, 1999b, 2004; Oderberg, 2019).

Ancient cultures, including the Egyptians, Greeks, and Romans, widely embraced the belief in an afterlife, closely linking individuals' spirits—known as *psychē* in Greek tradition—to their physical bodies and the objects they utilized during their lives. This profound conviction had a significant impact on burial practices. For instance, ancient Egyptians meticulously practiced mummification to preserve the body in a lifelike manner for eternal life, a practice that began intentionally around 2600 BCE (Aufderheide, 2003). Similarly, archaeological discoveries at ancient Egyptian, Greek, Roman, and pre-Colombian American Indian burial sites

reveal the importance of preparing the deceased for the afterlife, often by surrounding them with artifacts intended for use in the next existence. Ancient civilizations defined and confirmed death based on observable signs and deeply held beliefs. This review examines how five civilizations—Ancient Egypt, Mesopotamia, Greece, China, and early Islamic medicine—approached the concept of death, exploring their medical criteria, spiritual rituals, measures to prevent mistaken pronouncements, and how these compare to modern standards. A remarkable common thread across these ancient civilizations was the reliance on the cessation of vital functions, particularly breathing and circulation, as the primary signs of death (A. Whetstine & Leslie, 2008).

Ancient Egypt (c. 2600 BCE - 30 BCE)

In ancient Egyptian thought, life force was embodied by the *ka*, a vital essence breathed into a person at birth and sustaining life thereafter. Death was defined as the moment the *ka* left the body, making it a spiritual event, not merely a physical one. The departed *ka*, along with other soul aspects (such as the *ba* and *akh*), would continue in the afterlife, provided proper rituals were observed. Egyptian physicians observed bodily signs, understanding the significance of heartbeat and breath. The Ebers Papyrus (c. 1550 BCE) described the relationship between the heartbeat and pulses felt in the limbs. A stopped heart and "silent" vessels were a dire omen. One Egyptian text states: "the interior of the heart is weak if the heart… does not speak anymore or if the vessels of the heart are silent and give no indication to the hands". Egyptians also spoke of the "breath of life" animating the body and a "breath of death" leaving it, underscoring the importance of breathing. Thus, an absence of breath and pulse was a concrete indicator that the person's life-force (*ka*) had departed. Elaborate rituals surrounded death, including mummification, practiced intentionally around 2600 BCE, to preserve the body for eternal life. The heart (considered the seat of mind and emotions) was left in place or carefully preserved, since it would be "weighed" in the afterlife judgment, whereas the brain was removed, reflecting the belief that the heart, not the brain, was vital to life and afterlife. Priests performed ceremonies, such as the "Opening of the Mouth," to re-enable the deceased to breathe, eat, and speak in the next world. These rituals were not tests for death so much as responses to it, ensuring the *ka* and other soul elements were cared for (Taylor, 2001). The ancient Egyptians possessed advanced medical knowledge for their time, capable of diagnosing and treating a range of diseases, including dental, gynecological, and gastrointestinal conditions, as well as conditions such as diabetes and

cancer. Crucially, Egyptian healers understood the concept of *mtw* (vessels) linked to the heart, and they could assess their condition by examining the patient's pulse, indicating an early, albeit limited, recognition of the cardiovascular system's importance to life (Nummenmaa, Hari, Hietanen, & Glerean, 2018; Taylor, 2001).

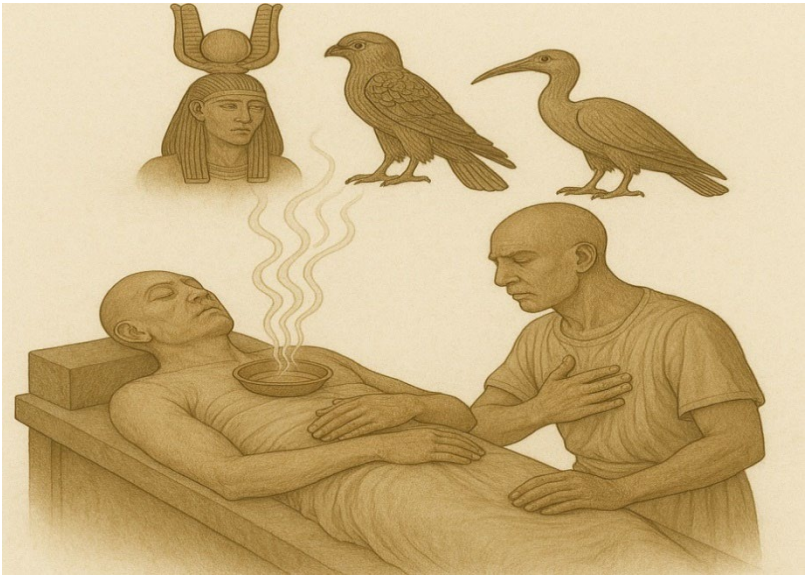

Fig. 2-3 In ancient Egyptian thought, life force was embodied by the *ka*, a vital essence breathed into a person at birth and sustaining life thereafter. Death was defined as the moment the *ka* left the body, making it a spiritual event, not merely a physical one. Illustration showing an ancient Egyptian priest checking for signs of life in a person lying down, with symbolic representations of the soul (ka) and gods above. In ancient Egyptian thought, life force was embodied by the *ka*, a vital essence breathed into a person at birth and sustaining life thereafter. Death was defined as the moment the *ka* left the body, making it a spiritual event, not merely a physical one. (Figure created by the author using AI)

Mesopotamia (c. 3500 BCE - 539 BCE)

The people of ancient Mesopotamia (Sumerians, Babylonians, Assyrians) had a stark view of death. To them, life was the animation of clay by divine components, and death the moment those divine elements withdrew. One Mesopotamian term for the human life force was *napīštu*, which meant "breath" or "life" itself. Accordingly, breathing was virtually synonymous