

# Introduction

## *Choreographing the End of Life*

Death is a universal component of the human condition, and one might argue that people everywhere attempt to die well, to achieve “good deaths” for themselves and their loved ones. However, definitions of what constitutes a good death differ greatly.<sup>1</sup>

Over the past century, death has become increasingly medicalized in many parts of the world—both in wealthy countries and more broadly, either through the ascendance of high-tech biomedical interventions,<sup>2</sup> or through their assumed lack.<sup>3</sup> The medicalization of death has, for the most part, been imagined as a universal good. After all, who doesn’t want to live longer or better, to stave off death as long as possible? But over the past few decades, there has been increasing attention to problems with medicalizing death. Many people around the world have debated the possible harms of prolonging dying.<sup>4</sup> And medical technologies, like the mechanical ventilator that pumped Jandi’s lungs, have unsettled the definition of death itself.<sup>5</sup> When does death occur? Is it when the heart and lungs stop working, or when the brain stops showing electrical activity? If one slows or pauses the deterioration of the human body, what happens to human experience? Is life improved, or is there simply more unnecessary suffering? How, moreover, should one relate to the dying, and how are we to relate to others as we die?

Despite increasing medicalization, medical technologies and expertise exist alongside other resources for navigating the dying process. I use the term “resources” to include conceptual and material possibilities: ideas

and things available when attempting to make death good. The goal of this book is to use Jandi's, Arirat's, and others' stories to understand how people attempt to achieve good deaths, particularly within the increasingly common global coexistence of Western biomedicine with other ways of approaching death.

To understand how Jandi and Arirat and their families attempted to achieve good deaths, I draw on the concept of social "choreography," arranging actions in the flow of time to make things (hopefully) go well. The concept of choreography evokes a dance that is partly planned, partly improvised, coordinating multiple different roles. Choreography is ubiquitous in human social life, which frequently involves irreversible actions that are dependent on one another.<sup>6</sup> More specifically to medicine, in what is called "ontological choreography," therapeutic technology is woven into life as a tool for making meaning and rearranging social relationships.<sup>7</sup>

In her book *And a Time to Die*, Sharon Kaufman argues that death in modern American hospitals has become structured by bureaucratic dependence on timing, so that both providers' and patients' conceptions of the "good death" have become linked to manipulating when death occurs.<sup>8</sup> Following Kaufman, many have used concepts about practice—strategy, coordination, improvisation—as complements or alternatives to the more classic bioethical approach of treating values as abstracted from context.<sup>9</sup> I use the term "choreography" partly because it captures many of these components of practice.

As Jandi's and Arirat's stories indicate, choreographing death is complicated and context specific. Their deaths were situated—unique not only to northern Thailand in the mid-2000s but also down to divisions between hospital and home, temple and street. Their deaths were also complex, requiring satisfaction of multiple, sometimes contradictory imperatives: the need both to pay back the debt of life in the hospital and also to allow body and spirit to separate at home; the need to respect one's elders but also protect their heart-minds, possibly by concealing the truth from them. And their deaths were shifting, occurring in a stream of transforming social factors, spurred by political events, changes in religion and medical expertise, and a host of global forces. Mapping Jandi's and Arirat's situated, complex, and shifting deaths requires a journey into many things, from biology to religion to politics.

One task of this book, then, will be to step into the particulars of Jandi's and Arirat's deaths, for it is out of the particulars that they come into relief: out of Jandi's family's "debt of life" and Arirat's "level of mind" and "karma master"; out of the collection of possessions at the

head of Jandi's bed; out of the ghosts, the monks, the nurses; out of the hospital and the home; out of the roles of the family and the individual.

A second parallel task of this book will be to help the reader sort through these details to understand more broadly the problems and possibilities that come from needing to choreograph death amid an array of shifting forces, especially the increasing medicalization of death in many places. How did choreographing death become so complicated in northern Thailand, with components like the harrowing spirit ambulance and the ideological tug-of-war about truth-telling and about what one should do with one's own "end of life?" And what can one learn from this particular context about death and dying everywhere?

To help with this task in this book, I use some of my own encounters with dying patients in the United States as a comparison. I conducted research for this book as part of a joint MD/PhD training program in San Francisco, California: two years of medical school, followed by a PhD program in medical anthropology (beginning with coursework, followed by two years of research and writing in northern Thailand from 2007 to 2009); followed by two remaining years of clinical clerkships to finish medical school, and eventually by an internship and residency in internal medicine. My training involved frequent tacking back and forth between medical training in the United States and research in Thailand. The result was a whiplash between worlds. It is this whiplash that I hope to share in this book, to help bring readers close to both the particulars and universals of death.

In my initial two years in medical school, before going to Thailand, I took electives in the medical specialty of "palliative care," a field focused on managing the dying process. I also trained as an "end-of-life doula," accompanying patients as an advocate and counselor through their dying processes. Palliative care was presented to me both as a medical specialty (with expert knowledge about medications and techniques) but also as a view of things somehow alternative to mainstream medicine: a way of paying more attention to meaning-making, to patient and family experience, to relieving suffering rather than just curing disease. In my electives, palliative care professors talked about most medical practice as involving too much "noise"—paperwork, time-pressure, routine—that seemed to melt away when the end of life was concerned, leaving only raw experience. I attended workshops on the "art of medicine" and "meaning in medicine," designed to inoculate me against the corrupting effects of reductionism and inhumanity in my medical training, to unearth and preserve my natural impulses as a holistic healer.

In retrospect, the tension between palliative care and other medical fields was exposing me to two strains of thinking within Western biomedicine: one was a reductionist, materialist, mechanistic, combat-oriented approach to diagnosis and treatment; the other was a largely Judeo-Christian notion of physicians and nurses as healers who accompany patients through the meaning-disrupting effects of illness, guiding them back into wholeness and dignity of spirit, even when the body might be beyond fixing.<sup>10</sup> Managing the dying process somehow seemed to induce dialogue and tension between these modes.

My central question going into my PhD fieldwork was how this complex set of ideas might be affecting other parts of the world, presumably with their own complex ways of approaching dying. For fieldwork, I settled on Thailand, a place with several features that promised to highlight encounters between biomedicine and “other” worldviews. The first feature was Thailand’s roots in Buddhism and Hinduism, distant from the Judeo-Christian and Enlightenment roots of Western biomedicine. Second was Thailand’s impressive universal healthcare system, allowing all citizens access to high-tech hospital medicine. Third was a feature of Thailand’s self-narrative, appearing everywhere from national health policy to soap operas and novels, as full of contrasts between “modernity” and “tradition”: remote villages with dirt roads and farming economies alongside urban hospitals with fully equipped intensive care units, radiology, and surgical capabilities.<sup>11</sup> I chose Thailand to explore this imagined contrast, to understand how people made sense of it, and whether it was a part of the strategies that they deployed to navigate the end of life.

From 2007 through 2009, I enrolled thirty-five terminally ill patients from a provincial government hospital, Nakhon Ping, just outside of Chiang Mai in northern Thailand, and then followed them through their journeys in and out of medical settings. My goal was to write participants’ end-of-life histories in as fine-grained detail as possible. I thus spent time with them at home and in hospitals and clinics, and interviewed them and their family members, often in multiple contexts and locations. I used their trajectories to determine whom else to interview: the nurses and doctors who cared for them, the monks who performed rituals at their bedsides. Following the threads of the things that showed up in individual deaths occasionally took me as far afield as to Bangkok and Southern Thailand to understand the trainings in palliative care and the national political landscape that had generated Arirat’s and Nurse Ampha’s claims about the “new end of life.”

My research design was based on several assumptions, and as is often the case with ethnography, these assumptions began crumbling upon entering the field. The first was that people would frame their understanding of the dying process in terms of a tension between biomedical and other forms of intervention. Instead, as Jandi's story makes clear, choreographing a good death required a mix of biomedical and other solutions, from mechanical ventilator to spirit ambulance. Biomedicine was one of many resources, repurposed into a complex strategy.

The second assumption was somewhat subtler, and was based on what my U.S. palliative care professors had claimed: that dying is an experience that needs to be managed, one that universally leads to a confrontation of deep philosophical questions. It is worth a brief anecdote from the beginning of my fieldwork to illustrate this assumption and its dissolution.

When I initially presented my work to the directors of Nakhon Ping Hospital, I faced the seemingly small challenge of how to explain my study topic. I settled on the phrase "the care of patients in the last stage of life."<sup>12</sup> If asked further, I could have explained my target study population: patients with terminal diagnoses who had a less than 50 percent expected six-month prospect of survival. But at first no one asked, and we seemed to be on the same page.

When I arrived for my first day at the hospital, the head nurse at the ICU told me that she had already identified three patients for my study, but that I would have to choose one because I wouldn't have time to study all three. Confused, I suggested introducing myself to them all and then working with them in an ongoing manner.

"But they are in the last stage of life," she said, confused, "they're going to die today." When I detailed my study population further, she looked disappointed, and said, "Oh, you're just interested in regular patients."

Over the subsequent eight months, this same confusion arose many times. Often, when I explained my patient population, a nurse or a doctor seemed to think my study unremarkable. Shouldn't I be studying "the last stage of life" instead? It seemed that my translation was incorrect, and that I would need to find a better word. I was trying to point to an interval of time that I imagined to be most important and relevant to an individual's death: a time when one knows that one will die but prior to the final physiological breakdown of the body.

I began asking nurses and doctors how to translate this term. Some claimed that there was no phrase that would encapsulate my study

population effectively. Others seemed familiar with my conception but framed it as a new idea arriving in Thailand. They would say, “Ah, you are studying ‘palliative’ [care],” or “You are studying [the] ‘end of life,’” with “palliative” and “end of life” said in English. Or they might even say, in Thai, “You are studying this new way of thinking about the last phase of life.” These comments often came with a reference to something that they had recently read or heard. This was the “new” way of approaching the end of life that Arirat and Nurse Ampha tried to teach me.

This phenomenon was much more complex than the “arrival” of a global field of palliative care in Thailand. Certainly, there seemed to be a status quo that was being disrupted by a “new” way of approaching things, linked enough to outside forces to have acquired an English title, “end of life.” But this “end of life” did not particularly resemble the way of approaching death that I had learned in my training in U.S. palliative care, or any global palliative care movements that I had encountered. In fact, both the status quo and the new approach to dying seemed to be inextricable mixtures of “local” and “global” elements, of biomedicine and other resources. Because of this, in this book, I follow recent analytic insights that the division between local and global obscures more than it reveals.<sup>13</sup> Instead, I think of deaths as *situated*, as specific to time and place due to particular combinations of social forces, some of which connect to a broader world.<sup>14</sup>

Jandi’s and Arirat’s stories provide a first pass at delineating the different ways of dying in northern Thailand. In a way, Jandi’s death represented the status quo, given that it did not incorporate the “new end-of-life” logic. As her family explained to me, and as I seek to show below, her death was divided into two phases. These phases were not precise, and often bled into each other, but they are nonetheless useful for sorting out the different ethical imperatives driving the choreography of death. The first of these phases involved aggressive medical care. In some ways, for Jandi’s children, it began when she fell ill, long before they managed to get her to the hospital. It was governed by an imperative to maximize, honor, and preserve life regardless of prognosis or chance for cure, to pay back the “debt of life” that they owed her for having been given life themselves at birth. They paid their debt through medical intervention and by “giving her heart-mind energy” (*hai kam-lang čhai*) to keep her from worrying and thus from harming her own body. This phase involved an important tension between the family and Jandi herself. Jandi resisted every time her family tried to take her to the hospital, because she did not want to be a burden on them, to let them

pay back their debt of life. They, on the other hand, were tenacious in their insistence on paying it, on taking her to the hospital. Even though it didn't prolong her life, this was all perceived as a success.

The second phase of Jandi's death was what the ICU nurse on my first day of fieldwork called "the last stage of life." It began when Jandi's physicians told her family that she would die in a matter of days or hours. When this happened, the framework governing Jandi's family's behavior shifted to facilitating the movement of her spirit to an optimal rebirth. This was dominated by a logic of place, because dying at home was essential to ensuring an effective and safe rebirth. Her death would occur when the elements of her body—earth as flesh, water as blood, fire as warmth, and air as breath—separated from her spirit. Her location at the completion of this separation would be partly responsible for the direction and quality of her rebirth. For Jandi, the hospital would have been a bad place to die, because it would have risked getting her stuck to polluted metaphysical forces. In contrast, her home was an ideal place to die, full of familiar people and possessions, and blessed by a history of moral family life.

After Jandi's death, in a way, this phase continued, through ceremonies controlled by officiating Buddhist monks, designed to further optimize Jandi's rebirth. These ceremonies transferred merit (*bun*)—spiritual benefit—to her disembodied spirit, largely to direct her into a beneficial rebirth, and also to keep her spirit from haunting the living. The concept of merit (*bun*) is based on the law of karma (*kam*)—that all actions have consequences: good actions produce good consequences, known as merit (*bun*), a substance-like force that can be generated, stored, spent, wasted, transferred, and used.<sup>15</sup> Jandi's rebirth, like all events (or more accurately, all consequences), was shaped by the balance of past actions attached to her. The function of her funeral ceremonies was to ritually add goodness to this balance, to positively affect her rebirth.

These "status quo" phases of dying required complex choreography, most dramatically manifesting as the spirit ambulance. They were also inextricable mixes of diverse resources: hospitals and ventilators and motorcycle tire pump embalmers; monks and rituals of merit-transfer; favorite possessions and components of the body.

Importantly, in these phases of Jandi's dying, death was conceived as taking place in a moment (the last breath taken at home), with a short logistical phase (the "last stage of life") meant to get her into the proper environment. Her death did not require her to know that she was dying or why.

The concept of “end of life” emerging in Nakhon Ping Hospital was different from these two phases of dying. It showed up as an activist agenda, intended to change the way that people perceived and performed the process of dying. Advocates for what Nurse Ampha called the “new end of life” proposed adding a phase, structurally different from the two phases of Jandi’s death. Arirat explained that because patients like Jandi did not know their diagnosis or prognosis, they would “have no chance to prepare their minds for the final moment.” Arirat was imagining an ideal type of person, an imagined figure,<sup>16</sup> who wanted to confront the difficult and suffering-laden reality of the end of life and use it to attain spiritual liberation. This process would take time, and thus required a new phase in the dying process, a time she called the “end of life,” when one should “meditate and chant,” “know what was happening,” and “prepare one’s mind.”

The sign on the wall also had an opinion about how patients should relate to illness: they had “a right and responsibility to know their disease, self-care for their disease, and treatment they were receiving for their disease.” The sign proposed a figure of its own—an ideal type of person who knew the truth and exerted her right to advocate self-determination in medical care. The sign also pushed the idea of an interval of time when one should know that one is dying, a time when one can actively engage and struggle with life-threatening illness.

Into the phases of dying encapsulated by Jandi’s spirit ambulance, the “end of life” had emerged as an imagined new phase—a period of time pried into the existing phases of dying, requiring a different way of being in the world.

In the chapters that follow, I present portraits of the life-worlds of those choreographing death in northern Thailand. This journey requires some conceptual tools, designed to help show how the particulars of specific deaths in one place relate to a broader world where death is changing for everyone. I draw these from various sources: from globalization theory, ethical theory, practice theory, and religious studies, among other fields. For example: how does globalization work—do outside forces flatten local experience, or do they form mixtures, like chimeras or creoles? Another example: how do people choreograph situations—do they follow well-defined scores, fumble their way blindly through, or not really have enough freedom of choice to choreograph at all? Yet another: do people use principles or other constructs to make decisions, and do they act as individuals or groups or something else? And if we take Arirat’s claim that her tumor was another being seri-

ously, how could she make medical decisions about a body that was not wholly her own? Rather than answer these questions in the abstract, I use them throughout the book to understand how individual stories reflect on the choreography of death in a broader globalizing world.

One piece of vocabulary worth building at the outset is the conceptual world of ethical theory. This is partly because throughout this book, I draw comparisons from my experiences in U.S. biomedicine, where end-of-life decision-making is overwhelmingly framed in bioethical terms. Many of the terms that I use in this book are self-evident: frameworks, imperatives, improvisation, persuasion, justification. But one problem with ethical terms is that many of them assume that people rely only on mental constructs to decide how to move through the world, ignoring the fact that real life is constricted by material conditions, and that people use different ideas in different situations. To account for this, I use the term “resources,” and the related term from ethics, “affordances,” to refer to the combinations of elements—mental constructs, material possibilities, and the vagaries of situations—available to those attempting to choreograph good deaths for themselves and those around them.<sup>17</sup>

Understanding Jandi’s and Arirat’s deaths will also require some conceptual tools particular to Thailand. It will require enough of an understanding of Thai Buddhism to explain the metaphysical mechanics of the spirit ambulance and karma masters. It will require enough of an understanding of Thai politics to make sense of why the death of a monk could lead to a new national movement around death and dying. It will require enough of an understanding of Thailand’s universal health scheme to make sense of why the deaths in this book were not plagued by material lack as much as they might have been elsewhere in the world. And it will require enough of an understanding of the connections between class, power, and spiritual hierarchy in Thailand to explain why Arirat’s “end of life” might be considered superior to other ways of approaching death. In this book, I weave these concepts together throughout on an as-needed basis.

This book follows the phases of dying in northern Thailand. Chapter 1 explores the “debt of life,” and how the biomedical hospital has become woven into the choreography of death. Chapter 2 explores the “last phase of life,” including using the spirit ambulance to ensure death’s proper location. Chapter 3 presents the phase of “the new end of life,” built out of a complex swirl of global expertise, national politics and religious practice. Chapter 4 explores the complexities of choreographing a good

death when one might be composed of multiple beings, such as Arirat and the tumor that she experienced as a karma master. Overall, the purpose of this journey into dying in Thailand is to understand the contemporary global phenomenon of the increasing medicalization of death, and the resulting complex world that people must navigate as they attempt to choreograph good deaths for themselves and others.