

The Uses of Dying:  
Ethics, Politics and the End of Life  
in Buddhist Thailand

by

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**The Uses of Dying: Ethics, Politics and the End of Life in Buddhist Thailand**  
**Scott Stonington**

**Abstract**

In Thailand, a series of global and local political events has destabilized the concept of dying and begun to replace it with a competing concept known as “the end of life.” As a result, the ethical frameworks governing the Thai deathbed have become disjointed. This dissertation is about the origin of these frameworks and how individuals, families and care providers navigate them. In Northern Thailand, dying has traditionally been conceived in two phases. First, from diagnosis until the hours before death, family members are driven by an imperative to pay back a “debt of life” to their relative by giving them “heart power” – support based on a unique model of the relationship between heart/mind, body and social world. The imperative to give “heart power” sets up an ambiguous relationship to truth-telling, which can drain heart power and hasten death. Second, the last hours of life are governed by an imperative to optimize the separation of body and spirit at the moment of death, best achieved in the familiarity of home rather than the metaphysically polluted hospital. It is into this ethical environment of these two phases that the new object “end of life” has arrived. In the 1990s, a military massacre of pro-democracy protesters and a scandal in the Buddhist clergy caused an opening in the traditional structures of Thai power. During this opening, the famous activist monk Buddhadasa died in the intensive care unit, against his wish for a natural death. Political and religious reform groups rallied around the Saint’s death as the focus of their interventions for Thai society. They proposed a set of new ethical figures: the figure of

the dying patient as a rights-wielding citizen, and the figure of the dying patient as seeker of wisdom. These ethical figures require a knowing subject and stretch the moment of death into a prolonged “end of life” that can be used for subject formation. These figures clash with the existing frameworks at the deathbed, which require an ignorant subject and conceive death as a moment. Individuals must navigate among these politicized ethical frameworks to make decisions about dying.

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## Note on Transliteration and Translation of Thai

Throughout the text, I have transliterated Thai words using the American Library Association/Library of Congress Romanization System, available at <http://www.loc.gov/catdir/cpsd/roman.html>, with the following modifications for typesetting purposes:

| ALA-LC Symbol  | Replacement (short) | Replacement (long) |
|----------------|---------------------|--------------------|
|                |                     |                    |
| U (vowel)      | eu                  | ēu                 |
| o (vowel)      | aw                  | āw                 |
| Ch (consonant) | j                   | -                  |
|                |                     |                    |

I have placed words directly Romanized from Thai in italics. I have not strictly Romanized proper names: for public figures, I have used the Romanizations chosen by their owners; for other characters, I have created pseudonyms, and have Romanized them loosely for ease of reading.

All translations, both of recorded interviews and published texts, are my own unless otherwise noted.

## Introduction

### Overture

“Can we talk English?” asks Jae. We are in a provincial hospital in Northern Thailand, home to some of the best public medical care in Asia. We are sitting on a rolled-out straw mat on the floor. Jae’s mother, Kiang, who is dying from lung cancer, is an arm’s length away, in and out of consciousness. “Her cousin had this [disease], before,” explains Jae, “If she hears us talk, she might guess.” Jae has not told Kiang that she has cancer, or that she is dying.

Jae lives in the Middle East and works for an airline. At her foreign job, she is lonely and feels oppressed as a woman, but she makes good money, which helps her care for her mother. She is one of only two children. Jae and I spend a lot of our time crying together, because she went abroad to provide her mother Kiang with opportunities to travel and be healthy, and now her mother is dying and won’t be able to take advantage of any of it. It is just plain sad. Jae is losing everything right now, and I can feel it.

I look from where we are sitting up at a large sign, the full length of the wall at the foot of Jae’s mother’s bed. It reads:

#### Announcement - Internal Medicine Special Ward - 6/4

- Things you have a right and responsibility to know during your stay in this hospital:
  - 1) Your disease
  - 2) Treatment you are receiving for your disease
  - 3) Self care appropriate for your disease

This sign makes me think of an article in this morning’s issue of the Bangkok Post. The National Health Commission has passed the first official medical law in Thailand,

defending a patient's right to refuse treatment. The newspaper article calls the law "the right to die," because choice of treatment at the end-of-life is the central bioethical issue at stake in conceiving the law.

I ask Jae in English about the sign on the wall, about her mother's 'right' to know. Jae replies, "A right to what? A right to know her disease, which can't do any good, can't be cured. A right to worry in her last days. That is not a right I want for my mother."

Kiang wakes up and says hello. She is full of softness. Everything about her is soft. She is a large woman, lying on an elaborate bed of pillows, into which her soft folded body gently sinks. Her smile is soft. Her consciousness is soft, too. Her daughters joke with her, and she smiles slowly and sweetly and then fades again. Her eyes drift open and closed. When they move Kiang to a new position, her body reforms to everything like sand. She is a sluggish aperture opening and closing to the world.

After telling me about her mother's right to peaceful ignorance, Jae walks to the bed to fuss over Kiang's pillows and make her comfortable. In response, Kiang smiles into her daughter's eyes.

"I don't think this disease is going away," she says, "I want to go home."

Jae grabs her hand: "We will beat it, mom! You have to fight, be strong. Keep your heart power up! Don't let it go!"

Hearing this in her daughter's voice, the dying woman's eyes fill up with warmth. I have learned that this is the bodily manifestation of 'filling up with heart power' – I can see it as I watch. I can't help thinking that this woman softly knows the lie being told to her and indulges it.

How did the announcement about patients' rights get onto Kiang's wall? Why is it the first item on the most prominent object in the room? And why is it completely and clearly ignored?

I step out into the hall to give Jae and Kiang a moment to themselves. In the hall, I run into Nurse Ampha, a poised, kind woman with scholarly round glasses. I feel like Ampha is a schoolteacher, and I treat her that way, since I feel like an ignorant and eager young student in Thailand and especially here in the hospital.

"What do you think about Kiang's case?" I ask her.

"It is not good," she says. I think at first she's going to talk about the lung cancer quickly colonizing Kiang's body. But instead, she talks about Jae's unwillingness to tell her mother her diagnosis. "Mother Kiang," she explains, "will have no chance to prepare her mind for the final moment. How can she know she needs to meditate and chant if she doesn't know what is happening? This is not a real 'end-of-life' case."

Ampha tells me about a lecture she heard at the Hospital Accreditation Conference in Bangkok about using the end of life to wake people up to the nature of their minds. It was one of many lectures she has attended about preventing burnout in the workplace by finding spiritual meaning in medicine again. Ampha looks exhausted from a long work shift in the understaffed hospital, but her eyes light and her posture rights when she talks about Jae's mother and the coming 'final moment.' Her eyes fill up and a smile comes to her face, and I can see that thinking about this fills her with heart power. But unlike for Kiang and Jae, Ampha's heart power comes from stepping forward to face the spiritual stakes of her patient's position at the edge of death. And Jae, by denying

Kiang explicit knowledge about her pending death, is also denying Ampha the opportunity to play this role at the end of Kiang's life.

“Why don't you tell her what [disease] she has?” I ask Ampha.

My nurse mentor shakes her head at me. “Her daughters are trying hard to do what is best, and they don't think their mother can handle the news. Telling Mother Kiang would disrupt the family and everyone's relationship and communication.”

Ampha is clearly sad about the spiritual consequences of this, but also respects the daughters and their process. “They know their mother and her level of mind,” she says definitively. “I don't.”

### **Kiang's Ethical World**

Kiang's room is inhabited by many things. It is inhabited by three women: Kiang, who lies softly dying of lung cancer in a high-tech hospital bed; her daughter Jae, who sits on a straw mat discreetly mourning her mother's pending death; and nurse Ampha, who worries from the hall for Kiang's soul. It is also inhabited, more abstractly, by a set of hovering concepts: heart power, level of mind, rights, knowledge. These concepts are available as frameworks for deciding what to do and how to relate to Kiang's dying. They are used for justification and persuasion. They are used to make sense of what is going on. They are concepts about right and wrong action. These features – decision-making, justification, persuasion, sense-making, right and wrong – place the concepts inhabiting Kiang's room in the domain that Western scholars have vaguely termed “ethics.” But in Kiang's hospital room, there is no single “ethics.” There are concepts and there are people – people negotiating right action out of ideas available to them.

Kiang's room is a small ethical world – a world in which different frameworks collide, fuse and clash – a world in which right action is unclear, in which push and pull between people and ideas determine Kiang's experience of dying. Jae does not want her mother to know she is dying. Nurse Ampha wants her to know. The sign on the wall “wants” her to know, too. Why?

The frameworks operating in Kiang's room are specifically tailored to the end-of-life. Some of them are new, and others are less new. Nurse Ampha's vehemence about knowledge and the soul were acquired this year at a government training in the country's capital. At the center of the training was the care of patients at the end of life. Similarly, the sign on Kiang's wall claiming her right to know orbits a national controversy over the right to die. How did dying become central to teachings about meaning in healthcare, and to debates about patient rights?

The simple task of describing the frameworks at work in Kiang's hospital room requires some complicated journeys. Some of their roots spread out to global debates and to national politics. Others, like the concepts of “heart power” and “level of mind,” live in a deeply local conceptual web. This dissertation is a study in the travel of what might loosely be called “ethics.” It is a study in the junctures and disjunctures, negotiations, fusions and mishaps that take place when ethical frameworks collide. It is about how ideas about right action travel, and what happens when they land in new places. It is about social change, about how Kiang's deathbed has come to be a place where people and ideas push on one another.

## **Ethics and Social Change**

Kiang's room is a small site of social transformation. New ideas have arrived and have begun to tug on older ways of thinking and acting. In her room, there is no settled "culture" upon which to draw. There are only questions and a set of unclear, competing models for what is right.

Societies and cultures change when, at moments in history, conditions come together to destabilize existing ways of thinking and acting. This creates a vacuum into which new elements rush. A tree falls in a forest and creates a clearing – not an empty space exactly, but a kind of negative pressure, a shifting of conditions that opens a space of possibility. Plants and seeds previously hidden in the underbrush activate and grow and eventually attain dominance. In a similar way, societies might be said to shift in shape when something destabilizes established ways of thinking and acting and makes space for new ones, or for new versions of old ones.

This process of social change is not random. For example, many scholars have observed that social change is accelerating in the contemporary world and is shifting in a direction vaguely understood to be "global," meaning that forms of power in particular places are increasingly being destabilized due to the flow of people and ideas from other places. And as these people and ideas cross previously impermeable boundaries, the traditional structures that those boundaries represent begin to destabilize – to lose their power, to have their validity called into question, or to be forced to renegotiate and justify their righteousness. For example, in negotiations between organizations and individuals from a diverse set of places, interested parties lose the ability to call exclusively on God (whose God?) or the Law (whose Law?) to convince others of their stances and guide

action. As with all social change, this globalization operates by way of a series of destabilizations and openings, each requiring interested parties to find new languages to argue for their agendas, new ways of making decisions and deciding how to be.

This is not to say that previous social forms disappear. In fact, religious and nationalist revivals are prominent reactions to the destabilization of religions and nationalisms. Previous social forms reassert themselves when their dominance comes into question. One might thus simply say that in social transformation, previous social forms become unstable, creating an opening and an incentive for interested parties to seek new ways of thinking and acting, or to bolster old ones. The openings created by globalization require a language that is sufficiently universal (or “global”) to be used by actors in widely different contexts – flexible enough to transcend those contexts’ differences, but firm enough to carry persuasive power and organize disparate groups of people and ideas.

On a global scale, scholars have identified many contemporary concepts rushing into openings created by the destabilization of previous social forms, including neoliberal economics (Barry 2004, Strathern 2005), biological science (Franklin 2005, Lock 2002, Petryna 2002, Rose 2001), vital systems security (Lakoff and Collier 2008), and humanitarianism (Palsson and Rabinow 2005). These concepts are constantly transforming and being renegotiated. Organizations, individuals, and state bodies assemble and disassemble around them, drawing upon them to form alliances, to hedge in conflicts, to form identities, to guide decision-making. They are “global assemblages” (Ong and Collier 2005) – evolving concepts and the practices, structures and elements that “assemble” together because of them.

Kiang's hospital room is not only inhabited by people and ideas, it is also inhabited by an emptiness, by an opening. And this opening touches on the things that Western social theorists have called "ethics": decision-making, justification, persuasion, sense-making, right and wrong. In other words, some force has removed the certainty about the right thing to do from Kiang's room. And into this opening, newly formed and still unstable assemblages have begun to rush: Ampha's meaning-in-medicine movement, her vision of Kiang as a seeker of wisdom, and the sign on the wall's vision of Kiang as a rights-wielding citizen. Where did these ideas come from? How did Kiang's room become a site of social change?

### **History, Death and Social Change in Thailand**

In 1991-1992, a cataclysmic political event occurred in Thailand that destabilized previous forms of political power and created an opening for new forms to emerge. In 1991, Army Commander Suchinda Kraprayoon led a military coup to overthrow a democratically elected government, and 200,000 protesters took to the streets. The military cracked down brutally on the protests, arresting and torturing thousands, killing hundreds. Images of the brutality hit the domestic and international media, forcing Suchinda to resign and creating an overwhelming political will that extended beyond Suchinda's reign into a galvanization of reform movements throughout Thai society. The events of 1992 created a sudden shift, calling into question the traditional political powers in Thailand and giving voice and action to those who would reform them. The following five years were a time of intense reform activity, ultimately coalescing in 1997 into a dramatically reformed constitution, termed the "People's Constitution" because it

inserted democratic ideologies to replace traditional forms of political power. The elements of this constitution and of the reform movement were built on a long history of reform in Thailand, but they also introduced new features. Most importantly, reformists were skeptical about their ability to effect lasting change through traditional forms of Thai thought, and so they reached increasingly to international discourses to bolster their arguments.

Meanwhile, in 1993, a second event occurred, the death of the famous Buddhist teacher and Saint, Buddhadasa Bikkhu. Since the early 20<sup>th</sup> century, Buddhadasa had been at the heart of social critique of Thai politics and religion. He had broken with the Thai clergy (*sangkha*) to argue against a Thai Buddhism based on ceremony, materialism and hierarchy for a religion based on individual practice, renunciation and justice. He advocated for a “socially engaged” spirituality, built on socialist ideals, and on a return to nature and meditation.

In 1993, the radical teacher suffered a stroke in his forest monastery. Prior to his illness, in religious sermons, personal conversations and written documents, he had clearly stated his desire to die a ‘natural’ death outside of the hospital, at home in his forest monastery. But after a long conflict among his disciples, he was flown to an academic hospital in Bangkok, where he spent six weeks on life support before an embittered decision to withdraw the machines and allow him to die. The Thai media and Thai public took up the great teacher’s death as a national issue both during and after his hospitalization. Many felt that the situation revealed a rift in Thai society between tradition and modernity, between lay beliefs and monastic beliefs, between individual

freedom of choice and community welfare. His death revealed deep lines of dissatisfaction and disagreement in politics, religion and the practice of modern medicine.

Buddhadasa's death landed into the heart of the opening created by the 1992 massacres. Because of the rich social issues at play in Buddhadasa's life and in the circumstances of his death, he became a locus around which various forms of social change began to assemble. Groups seeking to reform Thai Buddhism, Thai politics, and Thai healthcare began to coalesce around the Saint's death. And because their agendas were broad, they used the Saint's death in a broad way to influence Thai society as a whole. In the process of expanding their focus, they began to engage and critique the idea of death itself, claiming that death had become an important casualty of a corrupted modern Thai society. They began to propose a new ideal of dying, drawing on global concepts about rights, spirituality and end of life care. They simultaneously assembled around and began to transform death, to argue for a new kind of experience, a new kind of dying that would emblemize a more ideal Thai society.

Not surprisingly, because the nature of Buddhadasa's life and death involved power and knowledge, free will and tradition, these movements' new conception of dying also involved these things. The issues of free-will and self determination in the dying process became a locus for reforming Thai politics, for making true rights-bearing citizens out of Thais dominated by traditional forms of power. Dying became a locus for reforming Buddhism, making individuals investigate their own minds and face the realities of suffering rather than trust to ritual and tradition. It became a locus for reforming medicine, encouraging healers to face the social and emotional dimensions of medicine rather than the unrelenting imperative to cure.

Death suddenly came to be at the heart of Thai politics, religion and healthcare. And more precisely, a new object began to form, a transformed and idealized kind of death.

For hundreds of years, death has been an important object in Thai Buddhism, both as an object of spiritual contemplation and as a life transition whose navigation has profound spiritual consequences. Because of this, death is pervasive enough in Thai culture to appear in daily conversation and in the ubiquitous teachings of Thai clergy, available in the ordinary lives of Thai citizens.

Historically, death has played two roles for Thais. First, death as an idea, with the strong emotions that it generates, serves as a metaphysical and psychological antidote to obstacles to spiritual progression. The strong fear evoked by the idea of dying and the capriciousness with which death can befall anyone are used to shock individuals out of their “heedlessness” and motivate them into spiritual practice. Similarly, the strong revulsion that most people feel when they see images of death is used as an antidote to ego, lust and desire, to addiction to beauty and perfection.

The second traditional role of death is as a transition to future rebirth. For most Thais, the quality and location of one’s future rebirth is determined by the contents of the mind at the moment of death. Thus in the process of dying, the *moment* of death itself is paramount, and one should take care to fill the mind with spiritually advantageous thoughts.

Prior to the events of the 1990’s, death was an abstract idea to be contemplated or it was a moment in time that would govern one’s rebirth. As movements began to assemble around Buddhadasa’s death and into the opening created by the 1992 protests,

they began to transform death into a new object of concern for the Thai people: the “end-of-life” – an object emphasizing experience, individual knowledge and conscious grappling with the time before dying. The “end of life” became the center of new alliances between interest groups hoping to bolster or provide alternatives to Thailand’s destabilizing political and religious power structures.

This dissertation is not a study of Buddhadasa’s death. It is not a case study in historical events. It is simply an attempt to explain the frameworks that inhabit Kiang’s hospital room. Some of these frameworks exist in a local Northern Thai world – Jae’s imperative to keep her mother from knowing her diagnosis, and Kiang’s wish to die at home. But other frameworks, like the sign on Kiang’s wall and Nurse Ampha’s worry from the hall, are the product of social change in Thailand and of the new elements that are emerging out of it. Thai society is shifting its shape, and dying has come to be at the center of that shift. As a result, Kiang’s hospital room is full of unsettled questions and confusion.

Understanding Kiang’s room requires both an “anthropology of the contemporary” (Rabinow 1999, Rabinow 2008), and a “history of the present” (Foucault 1997), tracking ongoing changes in society, produced by the recent past. What is this new object in Thailand, the “end of life?” What effects is it having on Kiang’s death in the hospital? Are the frameworks in her room coherent, or are they full of disjunctures and awkward negotiations?

## Tools and Conversations

In this study of Kiang's room, I will draw implicitly on a diverse set of concepts emerging from the fledgling discipline of the anthropology of ethics. The anthropology of ethics was born from a fusion of moral philosophy to the age-old anthropological task of describing differences in value systems between groups of people. How do people justify actions and persuade one another of the right thing to do (Boltanski and Thévenot 2006) or the right kind of person to be (Foucault, Rabinow, and Hurley 1997)? What is the relationship between knowledge and moral goodness (Lakoff and Collier 2004, MacIntyre 1981)? What are the roles of cultural change and power in deciding what is right (Ong and Collier 2005)? These questions are abstract in the general but take on concrete and vital significance in attempting to understand the events taking place in Kiang's hospital room and crafting her experience of the end of life.

The anthropology of ethics is still immature as a discipline, and its vocabulary is still chaotic and confused. Studies have been plagued by contradictory attempts to define ethics as opposed to morality,<sup>1</sup> and ethics as social interaction as opposed to subject formation.<sup>2</sup> To cut through this semantic confusion, I will define and rely on a few simple terms.

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<sup>1</sup> As an example, Kleinman defines ethics as principles for behavior derived from hypothetical interactions between two actors; and morality as the messy, relational process of lived decision-making, the "the medium of engagement in everyday life in which things are at stake and in which ordinary people are deeply engaged stake-holders who have important things to lose, to gain, and to preserve" (Kleinman 1998)(362). In an opposite direction, Laidlaw defines morality as a set of rules or prescriptions for behavior, and ethics as making choices without rules to guide them (Laidlaw 2002). These two scholars' distinctions have dominated the anthropology of ethics and led mostly to confused semantic arguments. Moreover, by creating a distinction between "idealized philosophy" and "real decision-making," both scholars fail to see that real situations are interesting in large part because of the ways that people use simplistic principles in complex ways to move agendas, negotiate decisions and communicate relationships (Varenne et al. 1998, Wieder 1974).

<sup>2</sup> Foucault draws on the word ethics as the center of a research program on "care of the self" and "subjectivity" to draw attention to the ways that moral goodness involves a certain internal kind of subject-

First, how do people – dying patients and their children, policy makers, Buddhist reformers – think about the end of life? What concepts do they draw on to decide the right thing to do in the face of dying? To encapsulate these questions, I will use the term “ethical framework.” This is similar to Lakoff and Collier’s concept of a ‘regime,’ “a manner, method, or system of rule or government, including principles of reasoning, valuation and practice that have a provisional consistency or coherence” (2005). I add the word ‘ethical’ because the end-of-life requires practical decisions about right and wrong action. The phrase “ethical framework” thus refers to a provisional, internally consistent system that is used to choose courses of action. This is a precise way of framing the questions: why does Jae not want her mother to know she is dying? Why does nurse Ampha want her to know? Why does the sign on the wall “want” her to know, too? In other words, what ethical frameworks lie behind these perspectives and actions?

The concept of an ethical framework draws on many concepts used by scholars of the anthropology of ethics, such as “worlds of justification” (Boltanski and Thévenot 2006), “markets of virtue” and “politics of virtue” (Kelly 1991, Palsson and Rabinow 2005), “hierarchies of value” (Girard and Stark 2005), “cultural narratives” (Gordon and Paci 1997), “value spheres” (Weber 1946), and others. I thus draw on these works for tools to help describe ethical frameworks. For example, Boltanski breaks frameworks down into descriptive components.<sup>3</sup> From this set of components, I will draw

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making (Foucault 1994, Foucault, Rabinow, and Hurley 1997). His use of the word ethics is opposed to the use of the word in modern bioethics, where it denotes frameworks used to make decisions about how to behave relative to other people (Beauchamp and Childress 2001). This confusion has locked the anthropology of ethics into semantic arguments.

<sup>3</sup> Boltanski and Thevenot use the term “world” in a way roughly similar to my use of the word “framework” (Boltanski and Thévenot 2006). Their “world,” however, is very different from my use of the term “ethical world” in this dissertation. See below.

particularly on the concept of an ethical “figure,”<sup>4</sup> a hypothetical ideal person who adheres to and is crafted by an ethical framework. Ampha’s ethical framework for finding meaning in medicine imagines a health care worker who is inspired and invigorated by helping patients to face the hard truths of existence. The sign on Kiang’s wall, on the other hand, imagines an ideal patient who is a rights-wielding citizen. Each ethical framework proposes a different ethical figure, which forms part of its persuasive and justifying power.

Finally, I will draw on a third term – “ethical world” – to denote a particular situation, such as caring for a dying patient in a hospital. This environment may contain many people (patients, families, doctors, nurses, etc...), each of whom may be drawing on different (and sometimes multiple and confused) ethical frameworks. Moreover, each person may draw on different frameworks in different places (hospital vs. home, city vs. country, etc...) and different situations. An “ethical world” refers to the frameworks at play in a particular place and situation, like Kiang’s room.

### **Locations and Characters**

This dissertation is the product of two years of language study, fieldwork and writing in Thailand, from February, 2007 to December, 2008. During this time, I lived in Chiang Mai Province in Northern Thailand. I immersed myself in the lives of twenty people dying from severe illnesses, and in the lives of their families and caretakers. Intermittently, these people identified experts whose work might be essential to understanding their experiences, and so I traveled the country to interview experts,

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<sup>4</sup> My use of the word “figure” also relies heavily on the work of Paul Rabinow (Rabinow 2003).

tacking back and forth between individual experience and expert opinion. This back and forth helped me understand the frameworks operating in Kiang's ethical world.

Kiang's room itself was in Nakhon Ping Hospital, Chiang Mai Province's central public hospital,<sup>5</sup> where I worked for a year as the home site for my research. The halls and rooms of Nakhon Ping Hospital embody the paradoxes of Thai public healthcare. The hospital is home to state-of-the-art high-tech medicine: ICU's with life support and monitoring capabilities, a CT scanner, a hemo-dialysis suite. For things that the hospital does not have, such as MRI technology, pulmonary pressure monitoring, cardiac catheterization, transplant surgery, and radiation treatment, patients are referred to the regional hospital fifteen miles away at Chiang Mai University. But despite its place in a network of advanced medical care, Nakhon Ping Hospital has the feel of a rural province: crowded hallways, inpatient rooms overflowing into courtyards, short doctor visits, harried medical staff. It is thus home to social contradictions, as well. Hill tribe patients in full garb fill the halls, often with no one to translate for them. Patients who have had little access to modern medicine may find themselves suddenly strapped to cybernetic life support machines at the end of life. Ways of thinking and practicing acquired by doctors and nurses during training in Bangkok and in Western countries sit alongside specifically Northern Thai ways of thinking and practicing, creating modern/pre-modern and central/peripheral dynamics.

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<sup>5</sup> The public healthcare system in Thailand is structured hierarchically in a referral system. In order to be covered by the government health plan, patients must first go to a public health outpost clinic (*satānī anāmāi*); if the clinic thinks their problem is significant enough, or if they have an emergency, they go to their local community hospital (*rōngpayābān chūmchon*); if the problem requires specialty care, they are referred up to a provincial hospital (*rōngpayābān prajam jangwat*), and upward to a regional hospital (*rōngpayābān prajam pāk*) or an academic hospital (*rōngpayābān mahāwitayalāi*). Nakhon Ping is the provincial hospital (*rōngpayābān prajam jangwat*) for Chiang Mai Province.

Doctors and nurses helped me identify patients to invite into my study.<sup>6</sup> I contacted patients, individuals often in the midst of intensive hospital experiences. Then I followed them through the remainder of their lives, spending time with them at home, in temples, in clinics and in hospitals. Of people I approached to participate in my research, I received no refusals. Overall, I conducted ninety-five interviews with sixty patients, family members and caretakers. In the spaces between these interviews, I traveled and conducted fifty-four interviews with healthcare providers, administrators, politicians, civil society leaders and other experts, in nine different provinces in Thailand.

The vast majority of my communication took place in Central Thai, and I was able to conduct interviews and observations myself. But of the twenty patients I followed, six were rural-dwelling Northern Thais who spoke little Central Thai. Communicating with these patients was facilitated by my research colleague Tom Tem, who translated from Northern Thai into Central Thai. Tom Tem was also there to smooth out and clarify my questions, even in Central Thai. She then spent hundreds of hours transcribing recordings and working through the transcripts with me to assure that I understood and could translate them. She was also a great teacher and an invaluable friend.

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<sup>6</sup> I used a formal disease-based prognostic tool (see Appendix I) to help me explain the kinds of patients I was interested in studying. The laboratory information necessary to classify patients according to these criteria was often incomplete or unavailable, and I thus could not use the criteria themselves to recruit patients, so I relied instead on nurses and doctors to point me to appropriate patients.

## **The Dissertation**

This dissertation is a systematic exploration of the different frameworks that inhabit the ethical world of Kiang's hospital room. I trace each framework's history and evolution, and then discuss what happens when these frameworks meet in Kiang's room.

In chapter one, I explore the framework that impels Jae to conceal information from Kiang, and to push Kiang's treatment to the last. In chapter two, I explore the framework that impels Kiang to die at home. These two frameworks are neither traditional nor old, because they are deeply intertwined with high-tech hospital death in modern Thailand. But they do represent a status quo, the dominant way of approaching death prior to the social changes launched in the 1990s, and thus exist in an old-new dynamic with newer frameworks.

In the second section of the book, I explore the ethical frameworks emerging from the social changes in the 1990s. Chapter three is an introduction to the history that produced the events of the 1990s, and the types of reform that emerged from it. Chapter four introduces the first framework emerging from that reform, centered on the ethical figure of patient as rights-wielding citizen. Chapter five introduces a second framework, centered on the figures of patient and provider as seekers of wisdom.

Finally, in chapter six, I discuss what happens when these frameworks come into contact in Kiang's room.

**Section I:**

**Local Ethical Worlds:  
the Phases of Dying in Northern Thailand**

When I initially presented my work to the directors of Nakhon Ping Hospital, I faced the seemingly small challenge of how to translate “end of life care” or “palliative care.” I settled on “the care of patients in the last stage of life” (*kan dūlāe phūpuai wāra sutthāi khāwng chīwit*). If asked further, I would have explained the characteristics of my study population: patients with likely fatal diagnosis in the last year of their lives.<sup>7</sup> But no one asked. It seemed that, because of the tendrils of the new globalizing palliative care movement reaching into Thailand, we were on the same page.

When I arrived for my first day at the hospital, the head nurse at the Adult Intensive Care Unit 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 said I could always go introduce myself to them and their families and study them over the coming days.

“But they are in the last stage of life,” she said, suddenly confused about my research, “they’re going to die today.”

When I explained about my study population, she said, “Oh, you’re just interested in regular patients.”

Over the subsequent eight months, this same confusion arose countless times. Each time 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” (*wāra sutthāi khāwng chīwit*) instead?

This confusion did not occur with everyone. Occasionally, I would present my study to a nurse or a doctor, and they would say, “Ah, you are studying ‘palliative,’” or “you are studying ‘end of life,’” with the words “palliative” and “end of life” in English.

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<sup>7</sup> For a more thorough expression of my selection criteria, see Appendix I.

Or they might even say, in Thai, “you are studying this new idea of the last interval of life.” These comments always came along with a knowing look, or a reference to something that the speaker recently read or to a lecture recently attended.

This is more than a linguistic confusion. It is more than a mistranslation of global palliative care discourse in a local setting. My original research design was to study the ethical frameworks that govern decision-making in the months and years before dying, a way of conceptualizing the “end of life” that is common in health care settings in the United States. I soon realized that I was bringing this object with me and that it did not map unproblematically onto the intervals of time important to the experience of dying in Northern Thailand. And more importantly, I also began to realize that, even before my arrival, a concept of “end of life” similar to the one I was carrying with me had started to arrive in the hospital in the form of books and lectures. But the arrival of this new “end of life” was incomplete and clearly conflicted with a way of understanding death and dying already well-established in the experiences of people in Nakhon Ping Hospital in Northern Thailand. I realized in the first few days of my fieldwork that my first task would be to uncover the frameworks that structure the experience of the end of life, to reveal how those frameworks differ from new concepts that had begun to arrive in the hospital.

Dying in Northern Thailand is divided into three separate conceptual phases, each governed by its own ethical framework. The Thai phrase I had chosen to use in describing my research to the head nurse of the ICU – the last interval of life – invoked only the second of the three phases.

The first phase extends from diagnosis and prognosis to the last hours of life and is generally governed by an imperative to maximize, honor and preserve life regardless of prognosis or chance for cure. This imperative is driven at one level by love and affection and at a more formal level by a debt of life owed by family members to dying patients and by a desire of everyone involved to make merit by valuing life. The method for paying the debt of life primarily involves “giving heart power” (*hai kamlang jai*) to a dying patient, a unique conception of how bodies heal that involves a model of the relationship between “heart-mind” (*jai*), “body” (*kāi*) and the social world.

The second phase – what on my first day was called “the last interval of life” – begins in the last hours or day before death, and is governed by an imperative to maximize the movement of the dying person’s spirit to an optimal rebirth. This phase is dominated primarily by a logic of place, because dying at home is essential to ensure an effective and safe transition to rebirth.

After death, a third logic takes over, governed by Buddhist funerary doctrine and controlled by officiating Buddhist monks. Its purpose is to transfer merit to the now disembodied spirit, to conform to doctrine and thereby optimize the benefit accumulated for the rebirthing spirit.

The concept of “end of life” is not part of this established set of phases of dying in Northern Thailand. In fact, “end of life” is a new object, being created by an evolving assemblage of elements rushing into the openings created by Buddhadasa’s death and the events of the 1990s in Thailand. When I arrived at Nakhon Ping Hospital, I came with a related concept of “end of life” of my own, and thus I was part of the new assemblage.

The purpose of this section is to explore the ethical worlds of dying patients and their families in one local lived context of Northern Thailand. What frameworks do these three phases of dying generate for making decisions and understanding the world?

This understanding is necessary for asking the next set of questions about the effects of the new concept of “end of life” on Kiang and her experience of dying. What happens when frameworks about the end of life coming from other places land in this environment? What work, both on local practices and on the new object “end of life” itself, happens at the interface between these frameworks?

## Chapter One: Heart Power for Flesh, Blood and Breath: Economies of Life at the Deathbed

### The Debt of Life

My first week at the hospital, I met Peng, a man in his seventies dying of multiple organ failure. He was on a feeding tube for his failing gastrointestinal tract, a mechanical respirator for his failing lungs and blood dialysis for his failing kidneys. He wanted badly to go home, was constantly fussy and frustrated, and expressed that it was time to let go of his life. But his primary caretakers, his daughter and niece, had no thought of ending treatment.

“How do you know when to stop treatment?” I asked. “Could it be causing him more suffering (*khwām tuk toramān*) to be alive?”

“We have to give him as much life (*hai chīwit*) as possible,” answered his daughter, Bua.

In response to my confused look, his niece, Phai, interrupted to explain, “Our father gave us flesh (*nēua*), gave us blood (*lēuat*) and gave us breath (*lom hājai*). He gave us existence (*kamnōet*), and now we have a debt of life (*pen nī chīwit*). We have to pay down this debt (*chai nī*).”

“Oh,” I said, and then awkwardly in my still underdeveloped Thai, I said, “life is what matters... suppose your father was not good to you, and did not take care of you, or if you did not know him... would it be different?”

“It wouldn’t matter,” said Bua without missing a beat, “even if father were a dog, a swine, a buffalo, even if he beat us or abandoned us (*jāk rao*). Life is a debt and we have to pay it back.”

In later conversations, the two women helped outline for me what flesh, blood and breath meant in terms of concrete care for their elder. His feeding tube was a gift of flesh, his dialysis was a gift of blood, and his respirator was a gift of breath. I listed other treatments, and Bua and Phai helped me categorize healthcare by nodding and saying “yes, something like that” (*arai bāep nan*) as I fleshed out the scheme:

| Life Component | Examples: Ways to Pay Debt                                    |
|----------------|---|
| Flesh          | Nasogastric tube feeding, surgery                             |
| Blood          | Dialysis, blood draws, IV medications, pulse oximeter         |
| Breath         | Endotracheal tube, mechanical respirator, inhaled medications |

Table 1. Bua’s and Phai’s “debt of life.”

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Young relatives of other patients did not express the “debt of life” (*nī chīwit*) theory as formally as Bua and Phai, but they expressed a desire to repay their parent by giving life.

One family that I befriended was so adamantly aggressive with medical care for their father that the old man underwent three rounds of cardiopulmonary resuscitation despite his constant, terrified pleas to go home. Later, at the man’s funeral, I asked his youngest son about the decision to keep fighting for so long.

“In Thailand,” he explained, “our parents are our holy trees (*rom pō rom sai*), our Gods (*phra jao*). We have to give them everything, to the very end.”

“What do you mean by ‘everything’?” I asked, thinking to myself: *you didn’t give him what he was asking for most, which was to go home.*

He thought for a moment, and then said, “we have to give them life.”

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When I first arrived in Chiang Mai to settle down for my fieldwork, I set out on a bicycle to find an apartment in the back alleys behind the University. In a small blind passageway lined with mango trees, I ran into three young brothers running a food stall, selling grilled pork and green papaya salad. I sat with them and ate their food and juggled a football, and made small talk, saying nothing about my research. We exchanged phone numbers. Later that evening, I received a panicked phone call asking me to return to the brothers’ food stall. I rode out to meet them, and was greeted by the youngest of the three, named Yai.

“We are from Northeast Thailand (*isān*),” he began nervously, and there was an awkward pause. He seemed worried about putting me out by calling me across town on a bicycle. “My uncle is very sick. They say that he needs a lot of blood transfusions.”

“What is he sick with?” I asked.

“The doctor says he has end-stage liver cirrhosis. He has been sick for a long time, but now he needs a lot of blood.”

“I’m so sorry,” I said, “it must be hard to be so far away from him.” There was a long silence as I waited for him to continue, hoping to see the purpose of the conversation.

Eventually, he began again, “There is a problem. My uncle is blood type B-negative and B-negative blood is very rare in Asia. They say that they can’t keep transfusing him so much because they don’t have enough blood.”

Another pause.

“I looked on the internet and they say that B-negative blood is more common among Westerners (*farang*). Do you know what blood type you have?”

I told him that I was O-positive, but that I could help him contact other Westerners in Chiang Mai if he needed me to. But I was still confused. What was Yai’s plan, exactly? *Isān* was twelve hours away. Matching blood is not a simple process of a one-to-one transfer, and requires a blood bank. Clearly, the plan was not coming from Yai’s uncle’s doctors, and I suspected it was an invention of Yai’s own.

When I asked about the plan, he said, “I don’t know, maybe someone could give blood here, and we could transport it there.” He paused again, and I could see in his eyes that he had not thought this through, but that he was desperate to do *something*. “My uncle raised us after my father died,” he said. “He is my closest blood relative (*chēua*). And he fed me when I was little and sent me to school. Now he is dying and I have to pay him back for the life he gave me.”

We used Yai’s cell phone to call his aunt in *Isān*, where she was sitting by her husband’s bedside in the hospital. She handed the phone to Yai’s uncle’s nurse. I asked about the man’s status and about the problem of transfusions. The nurse said that he did indeed have B-negative blood, but that he was already in liver failure and that they could not keep up with transfusions. Other systems were failing, too. I could hear her smile

affectionately and dismissively on the other end of the line when I explained Yai's scheme. "He has a debt to his uncle," she said, "and he is trying to pay it back."

I asked Yai why he thought that blood was the way to save his uncle, and he said, "I have to pay him back for my life, and giving him blood is the only way I can think to do it."

Yai had a debt of life to his uncle, and the way he thought to pay it back was to find a piece of life, a transferable living object – blood – and mail it to his uncle.

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Bet's mother left her when she was young, and she and her older sister were raised instead by their father. Bet spent most of her life angry at her mother for leaving them. Her mother's name was Hawm, and she saw her every few years, but it was always a painful and awkward occasion. Hawm had re-married. Bet heard that the man was kind enough but barely ever spoke. This new man and Bet's mother Hawm were not part of Bet's life. Bet had become an energetic woman in her twenties, running an export sales business and teaching art to kindergarteners on the weekend. But she was always anxious, and had trouble sleeping. She was nervous and lonely.

Bet's mother Hawm was diagnosed with pancreatic cancer, and I first met her when she was already lying in a hospital bed, unconscious most of the time. The cancer had begun to obstruct her bile duct and so her skin had turned yellow and her blood was slowly turning toxic.

Although they had never met, Hawm's husband tracked down Bet's phone number and called her. Bet rushed over that evening and sat by her mother's bed. For

the following days, she cancelled work for a half-day each day and came to care for her mother.

It took me some time to get to know Bet. She told me hours and hours of intimate things about her life and her sorrow about her mother. It was only after all of this that I felt comfortable asking the real question on my mind: “Why are you spending so much time caring for your mother when you never knew her?”

She smiled, and said, “I know... it’s strange isn’t it? When I first heard the news, I thought: *I don’t even know her*. But then I thought: *she’s my mother!* She gave me existence, she gave me life. I have to pay her back.”

She paused for a moment. “It is hard, though. I have never had any *phūkphan* with my mother. I look at her and feel nothing, not angry, not sad, just nothing. I only feel like I have to pay back my debt of life.”

*Phūk* means to tie or to fasten. *Phan* means to wrap around. Together they mean a kind of tie of affection, something that would link Bet to her mother, make her sad to lose this person who has grown in her heart. *Phūkphan* also means “obligation,” and it is the kind of obligation that comes from loving someone, from owing them part of yourself, and from needing to show this love to the world.<sup>8</sup> Most people who pay back their debt of life to a loved one also have *phūkphan* with them, and the two mix together into a dutiful and loving kind of care.

That day, when we left the hospital ward, Bet checked as she walked by to see if her mother was awake. Her mother was sleeping, so she turned and walked out without saying goodbye or touching her. The intimate affection of touching or gazing at her

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<sup>8</sup> As the daughter of one patient said, “if we didn’t do all of this [medical treatment], people would say that we don’t care for him, that we have no *phūkphan* with him.”

sleeping mother was not part of Bet's debt of life. If her mother was awake, she would do whatever she could to care for her, but there were no private moments, no intimacies like sitting and taking her mother into her heart and memory, just for the satisfaction of being next to her.

The next time I saw Bet, we sat out on the balcony of the hospital ward, and she started to cry. "I was angry at her my whole life," she said, "for abandoning me when I was only one year old. I barely know her. She never kissed me or hugged me or gave me anything. But yesterday when I came she kissed me on the forehead. It was the first time." We walked back into the room. Bet's mother was unconscious, but this time Bet walked over and put her hand on her mother's arm and sat there, holding her like she could feel the life pulsing through her.

Many weeks later, after Hawm had died, I said to Bet, "It seemed like you developed some *phūkphan* with your mother in the few days before she died."

"Yes," she said, and teared up. "It was a great gift."

We sat in silence. I thought about the debt of life that Bet had always already owed her mother. It brought her, despite estrangement and anger, to her mother's bedside to give her mother the life that had been given to Bet at birth. But through the fulfillment of her duty, Bet generated a store of *phūkphan* that she could carry for the rest of her life.

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When I first began to watch people pay down their debts of life in the hospital in Northern Thailand, I thought that the purpose of people's actions was to cure their loved ones. Bua and Phai wanted to give Peng everything that modern medicine had to offer

for his multiple organ failure: mechanical respiration, dialysis, a nasogastric tube for feeding. These things sustained his organs and prolonged his life somewhat. But Bua and Phai knew that Peng had reached a point of no return from his diseases. He was already unconscious, and his body was going into system-wide failure. His death was only a matter of time.

Bua and Peng never used language about end-points to justify their actions. They never said “we want to cure his disease.” Instead, they referred to their own need to act. “We have to pay our debt of life.”

Yai knew that giving his uncle more transfusions could not cure his cirrhosis. His uncle was already unconscious from the poisons building up in his blood, but Yai did not talk about wanting to have one last conversation with his uncle, or some procedure that remained to give a hope for cure. Yai needed to give his uncle a living object, blood.

The ethical framework organizing Yai’s and Bua’s and Phai’s actions was not about a result. It was about a process. And this process was an economy, a transfer of life. The outcome was less important than the transfer itself.

The core of the first framework governing death in Northern Thailand, the first framework inhabiting Kiang’s ethical world, is about an economy of life. Kiang's daughter Jae needs to pay down the debt incurred by receiving her existence from her mother.

## Heart Power is Life

My favorite fieldwork question for relatives of a dying patient was, “what does your relative need most right now?”

The answer was universal: “heart power” (*kamlang jai*).

In the midst of discussions with patients about an extraordinary array of topics – surgery, finances, memories – family members would interrupt me and say: “you know, none of this is important... the most important thing is heart power (*kamlang jai*).”

The word *kamlang jai* is difficult to translate, as is true with all words that incorporate the word *jai*, which means both ‘heart’ and ‘mind.’ *Jai* is the seat of emotion and reason, and it is located somewhere just below the diaphragm. When Thai people say, “I was thinking about...,” they generally place their hand on their chest or their abdomen, not on their head.

At first, I took “heart power” at its face value, its dictionary translation: morale, or spirits (as in: “he’s in good spirits”). I began logging the phrases that incorporate the words “heart power”: “to give heart power” (*hai kamlang jai*), meaning to encourage or boost morale; “to run out of heart power” (*mot kamlang jai*), meaning to despair or lose spirit; “to be heart power for someone” (*pen kamlang jai hai*), meaning to inspire or support.

Several days after meeting Mr. Mahu, I sat with his granddaughter Pheuak talking about potential surgery for him. We talked about the mechanics of the surgery, and the disease pathology and why cutting out his tumor might help. I asked, somewhat suddenly, “what do you think he needs most right now?” And she, of course, answered “heart power,” but as she did so, she moved her hand down to a spot on her abdomen and

turned it slowly like a churning turbine under her diaphragm. I had seen this before when people talked about heart power.

“What are you doing?” I asked. She and I were the same age and she was warm and kind, and I felt comfortable enough to push on some ideas, knowing that she would not shy from them and could help me understand.

“When you have heart power,” she said, churning her hand over her diaphragm again, “it makes you have mindfulness (*sati*) and concentration (*samāthi*) and be with your heart (*yū kap jai*), down here, and it is calm and quiet.”

“And why is heart power the most important thing? We were just talking about surgery... isn’t surgery important?”

“Without heart power, the surgery won’t work,” she said, explaining an obvious principle to a child. “If grandfather runs out of heart power, he will think too much (*khit māk*), and thinking too much harms the body. We have to give him heart power, so he will live in his heart (*yū gap jai*) and not think too much, and this will cure him.”

Although Pheuak’s ultimate goal was to give her grandfather life – in this case, to cure her grandfather of his cancer – she was worried that his "thinking too much" (*khit māk*) would make the cancer grow and weaken his body. Filling him up with heart power (*kamlang jai*) would suppress this thinking by allowing him to be with his heart (represented by the twisting fist beneath the diaphragm). In this theory of human consciousness, the heart is like a vessel, and it can be full or empty. When it is full, it is easy to be with it, to dwell comfortably in it. But when it is empty, it is difficult to be with it, and one begins to think too much. Pheuak’s family’s job was clear: to fill their grandfather with heart power, preventing him from thinking too much, thereby curing his

body and paying back the debt of life they owed him from the life he had once given them.

When Jae leapt to her mother Kiang's bedside, she said "keep up your heart power, mom!" Alongside aggressive medical treatment, maintaining her mother's heart power was part of Jae's imperative to repay her debt of life to her mother. The first ethical framework inhabiting Kiang's room, then, has as its core principle the imperative to give life. But the mechanism of giving life is to provide and maintain heart power.

### **Truth, the Mind and Heart Power**

Of the twenty patients that I followed closely, all but three were kept ignorant of their prognosis and their diagnosis for the duration of their illness. In all of these cases the justification for concealing the diagnosis was that the patient would suddenly “run out of heart power,” and that this would “shock” the patient to death.

The primary principle underlying the ethical framework of caretakers in the first phase after a potentially fatal diagnosis is to give life, to pay back their debt of life. The most important way to do this is to give a patient heart power so that she “doesn’t think too much.” This relationship between thought, the heart and the body sets up an ambivalent relationship to truth.

On my first day at the hospital, I went around to every medical and surgical ward and introduced myself to the nursing staff. At one ward, the nurses eagerly descended upon me. “We have a patient for you now, we are so glad you’ve come, maybe you can help give heart power to this patient.”

His name was Nanban, and he had come in coughing blood and they had discovered stage 4 lung cancer. Would I like to meet him? Of course.

Standing outside the patient’s room, the nurse said off-hand, “oh, but be careful when we go meet him, because he doesn’t know what disease he has or how bad it is,” and by her intonation, I knew that by ‘how bad it is,’ she really meant *he doesn’t know that he’s dying*.

My heart rate leapt up... I was going in to introduce my research to a patient who knows nothing? She opened the door and we walked in the room, and upon seeing a foreigner, Mr. Nanban’s son and daughter leapt up from their straw mat on the floor to

intercept us. The nurse introduced me, “this is Scott, he has come to do research, I want to introduce you to him.”

I watched panic run over Mr. Nanban’s daughter’s face... *research, meaning research on cancer, he’s going to say the word now...*

“Hello,” I said, “I am here to study the experience of very ill patients in the hospital.” I presented my consent form. “I just wanted to leave some information with you and meet you... I’ll leave this form for you to read and think about, and I will be back on Monday.”

The daughter looked instantly relieved that only benign words had come out of my mouth. But she quickly said, clearly embarrassed and regretful that she couldn’t be more welcoming, “I don’t think we will want to participate.”

I left, thinking to myself *this is going to be very hard.*

On Monday, I arrived to the same ward, and the nurse pulled me aside, “Scott, where have you been!? Mr. Nanban’s family has been asking for you all weekend! They want to participate in your research.”

I couldn’t have been more shocked, based on the interaction from three days before. “Why?” I asked.

The nurse lowered her voice and pulled me aside. “The doctor accidentally told the patient he has cancer, and now Mr. Nanban has run out of heart power, and he is worsening fast. The family needs you to help give him heart power.”

I spent the next three days with Nanban in the hospital, sitting with his daughter Buaphan and son Sak, talking in whispers about their father’s condition, and then after he was discharged from the hospital, I sat with the family in their mountain village holding

vigil over him for his last night of life. Much later, I drove through the mountains with Nanban's daughter after her father's death.

“The doctor killed my father,” she told me, “by telling him what he had [cancer]. My father ran out of heart power. The words the doctor used made my father think too much, and so he died. Too fast! There wasn't even any time to say goodbye.” And as we drove the mountain road together, we sat in silence about how sad this was.

Buaphan's ultimate goal was to give her father life to pay back the debt of existence she owed him, and because she loved him and had such a tie of affection (*phūkphan*) with him. The best way to give him life was to fill him with heart power to prevent him from thinking too much.

This ethical framework made truth a dangerous force in caring for Nanban. The truth destroyed his heart power, made him think too much, and killed him.

When trying to explain heart power to me, some patients fused it with a second term: *khwan*, which translates roughly as “animating spirit.” Most living things are infused with an animating spirit. A rice field is vibrant and productive because it is infused with the *khwan khāo*, the animating spirit of rice. In humans, each organ is infused with a *khwan*, and there is a chief *khwan* that resides in the swirl of hair at the back of the head and is responsible for personality and vitality.<sup>9</sup> If a *khwan* becomes frightened or disrespected, it may flee and leave the organ or person that it animates anemic and lifeless. A fled *khwan* leads to illness and the *khwan* must return for vitality to be restored.

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<sup>9</sup> In the areas where I studied in Chiang Mai Province, most people said that a total of 32 *khwan* animate the human body. This detail seems to vary by place in Thailand.

Most scholars describe the history of Thai metaphysics as a baseline of animism punctuated by inflows of Hinduism and Buddhism from South Asia (Keyes 1987a). Theory of mind is a perfect reflection of this history. *Khwan* is a deeply animistic concept, and it exists alongside the concept of *winyān*, or consciousness, inherited from the Vedic religions. *Winyān* is the being-ness of a person – the thing that remembers and decides and contains morality. *Winyān* is the entity that is reborn.<sup>10</sup> *Khwan* is simply the provider of energy and vitality.

When talking about how to pay back their debt of life, most patients simply referred to heart power (*kamlang jai*). But a few people, to help me understand how heart power works, used a fused term: *khwan kamlang jai*. Heart power, they explained, is like the animating spirit of the heart, and just like any other *khwan*, it can suddenly flee and leave the heart weak and indolent.

In Buaphan’s explanation of what happened to her father Nanban, truth was a dual danger. Primarily, it made him think too much, which harmed his body and made him die quickly. Simultaneously, it “shocked” the heart power out of him. It cracked the vessel of his heart and drained it of power. Because of this, his heart had no vitality, and he could not be with it. And so his thinking ran wild and destroyed his body. Once his heart was empty of power (*mot kamlang jai*), they could not get it back fast enough to save his life.

The first ethical framework inhabiting Kiang’s hospital room consists of an imperative to pay back a debt of life. The best way to pay back this debt is to ensure that the patient maintains his store of heart power. And because of the understanding of the

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<sup>10</sup> When a person dies, the *khwan* that animated that person and her organs all disperse off and animate other things. But the Buddhist concept of rebirth usually only refers to the rebirth of the *winyān*.

relationship between heart/mind (*jai*) and body (*kāi*), knowledge and truth-telling are at the heart of decisions about the way to maximize heart power and thus life.

Out of this system, the conflicts in Kiang's room come into relief – the clash between Jae, who wants her mother to remain heartfully ignorant, and Ampha and the sign on Kiang's wall, both of whom want Kiang to know her diagnosis.

The theory of mind underlying the first ethical framework for the end of life in Northern Thailand creates, at best, an ambivalent relationship to truth. Telling Nanban about his illness made him lose heart power, which killed him. Does telling someone that they have cancer ever *give* them heart power? Is the truth ever part of the project of paying back a debt of life? Perhaps. But it would take a particular kind of person, a person with a mind for whom a tragic truth would *help* them to be with their heart and *not* think too much, for whom the truth would have the opposite effect that it had on Nanban.

## Level of Mind and Case-Based Ethics

When I first met Mali, the idea of her was introduced to me by Nurse Ampha. “You have to meet Mother (*māe*) Mali,” she said to me, her eyes twinkling, “she is our first real ‘end-of-life.’”

“What do you mean by ‘end-of-life?’” I asked, by this time suspecting I knew.

Nurse Ampha was used to my silly repetitive questions and didn’t hesitate. “Mali,” she said, “knows what disease she has and wants to face it peacefully with meditation.”

What Mali “had” was pancreatic cancer, and she was at the hospital for a surgery to de-bulk the tumor – a surgery that had failed because the tumor was wrapped around a large blood vessel and the surgeons didn’t want to risk damaging it. Pancreatic cancer is legendary for causing fast and painful death, but I could see in Nurse Ampha’s eyes the excitement of what could happen if Mali were truly a good meditator. “She could face her death peacefully,” explained Nurse Ampha. “She might even hone her mind further. She is a very experienced meditator.”

Nurse Ampha warned that a group of Mali’s friends had come to visit her, so there would be a crowd in her room. “But you will know who she is,” she added before I walked in.

The room was full of people, milling and talking excitedly, but Nurse Ampha was right: I instantly knew Mali. She sat amidst the noise with a palpable calm, her eyes alighting on me with energy and a knowing, wise smile, and the room went softly quiet for a moment, and I thought to myself, *I have never been seen like that*. She was slightly jaundiced from her surgery, but her glow was something very different from the yellow I

have seen in many patients before – it was a glow of an undeniable inner calm and joy and she was able to pass it instantly on to me when I entered the room.

“Welcome,” she said, “the nurse said you would come. Please have a seat.”

Over the following months, I spent dozens of hours with Mali, much of them learning Buddhist ideas from her as a teacher, and much of them talking with her about standing at the edge of death.

That first day, however, because of her friends’ presence, I didn’t get to ask many questions. One of the few questions I asked was: “when did you know your diagnosis?”

“From the very beginning,” she said. “They told my husband first, but he knew I could take the news, and that I could meditate on it, so he made the doctor tell me right then.”

Eventually, the pain of her disease forced Mali to meditate constantly. She would take occasional breaks to talk to me or to sleep, but the pain would return during that time and eventually be disturbing enough that she would excuse herself or wake up and return to meditating.

She and I spent many hours discussing pain and how it fits into spiritual practice. “This disease,” she said, “has been the greatest gift to me. I am happier and calmer now than I have ever been in my life.”

Later, I sat down with Mali’s sister, and once again, while we were talking about surgery, she interrupted me to say, “You know, none of this is important. The most important thing is heart power.”

I asked her to explain the word “heart power” to me, and she described a theory similar to Pheuak’s and Buaphan’s, with one important difference. “We give her a lot of

heart power,” Mali’s sister explained, “by caring for her and bringing her things, but most of her heart power comes from her meditation. She uses meditation to be with her heart (*yū gap jai*).” She cupped her hand into a fist and churned it gently under her diaphragm to illustrate how this would feel. “Meditation calms her mind and keeps her from thinking too much. It heals her body. That will give her life, it will cure her.”

Mali’s sister painted a modified portrait of heart power, where meditation is an internal way of being with the heart and thus keeping the mind from thinking too much and harming the body. Like in Buaphan’s explanation about her father Nanban, Mali’s sister’s primary goal was to give Mali life, and the most important way of doing this was by maximizing Mali’s store of heart power. And like in Buaphan’s explanation, Mali’s sister said that heart power would work by stopping Mali from thinking too much, which would harm her body. But unlike Buaphan and Nanban, the main source of heart power for Mali was not from the outside – it was from meditation, from an internal set of skills that allowed her to increase and hold onto her own heart power. And because of this, the effect of truth on Mali was the opposite of its effect on Nanban. Mali needed to know her diagnosis and her prognosis in order to meditate, to give herself heart power.

Buaphan and Pheuak and Mali’s sister operate on an ethical framework that has at its root a theory of mind, an understanding of the structure of human consciousness. Their imperative is to give life to the dying patient. The mechanism of that gift is to fill them up with heart power and keep them from thinking too much. In this theory of mind, truth is a vitally important force. But it is not an absolute force. Instead, truth is ambiguous, and its effect depends on the mind of the ill person. For some individuals,

knowing their diagnosis would cause them to lose heart power and die, and for others, knowledge is a necessary step to maximizing heart power and preserving life.

Truth and truth-telling, then, are not principles that arise out of the ethical framework of giving life. Instead, truth is case-dependent – it depends on the particular mind of each individual. If truth would cause the loss of heart power, then it must be concealed. If truth would increase heart power, then it must be revealed.

What, then, was the difference between Nanban and Mali? Why did the truth kill Nanban, and why did it save Mali?

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One afternoon, I sat quietly in Mali's hospital room. Her sister, husband and mother were there. We had been discussing many things lightly – meditation and cell phones and our favorite noodle shops, and then we were sitting in one of the comfortable silences we had developed from spending so much time together. Nurse Ampha came into the room. Seeing me there, she continued a conversation from earlier in the day about the case of Nanban and how his daughter felt that the doctor had killed him by telling him the truth.

When Mali heard that Nanban's family had wanted to conceal his diagnosis from him, she said: "that is so sad! If the patient doesn't know about his disease, how can he take care of himself? How can he eat the right foods and take the right medicines? And he has no chance to meditate and prepare himself."

"Some patients," replied Ampha, "cannot take the news. It is too big a shock for them. They lose heart power and get worse quickly."

Mali nodded her understanding to this explanation. “I guess it depends,” she said, “on the patient’s level of mind (*radap jit*).”

The attribute that differed between Mali and Nanban was their level of mind (*radap jit* or *sapāwa jit*). According to Ampha, when I asked her about it later in the hall, Mali had a high level of mind – she was resolute and resilient (*jai kaeng*). But Nanban, whose heart power vanished on hearing the truth, was soft (*jai āwn*). Ampha attributed this difference to personality (*bhukhalik*), to habits (*nisāi*) and to spiritual practice.

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An interesting strategy, at the beginning of my research, was to present doctors with ethical scenarios, usually starting simple and moving to more complex situations.

“Do you tell your patients that they have cancer?” I often asked doctors.

The answer was always some version of: “It depends on their level of mind (*radap jit*). What will the news do to them?”

“How do you know what their level of mind is?” I would ask.

“It is difficult... only the family really knows the patient well. So I tell the family and let them decide.”

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When Nanban’s doctor accidentally slipped and told him that he had lung cancer, Nanban got worse and lost consciousness within a few days. Nanban’s son and daughter, Sak and Buaphan, told me that the doctor had “killed” their father because he was not ready to hear the truth about his disease, and the truth “shocked” him to death. He lost all of his heart power, and began thinking too much, and it killed him.

In the midst of Nanban’s worsening illness, I sat by his bed and talked with Sak about what was going on. The bedside table was stacked with books of Buddhist teachings that Sak read to his father round the clock.

“Are these books particularly about this situation?” I asked Sak.

“No, they are just the books that grandfather has loved most throughout his life. We read them to him because they are familiar and give him heart power.”

I reached over and picked up the top two books from the stack. The first title was *When we Die, Where do we Go? Abbot Budatawarai can Recall Seven Lives*. The second title was by Buddhadasa, *Relief for Every Illness*.

Sak saw me looking at the books and explained, “Grandfather was a great Buddhist practitioner. He studied his whole life and he was a monk at Lūang Pū Sim’s monastery [a practice-heavy forest monastery].”

“Wow,” I said, “grandfather has been studying these books his whole life. Doesn’t that help him be ready to hear the news about his illness?”

Sak shook his head sadly and we sat for a while in silence. “Father has read and understood these books.” He paused, and then recited the familiar Thai refrain about the pervasiveness of suffering in all things: “Life is birth, old age, pain and death (*gōet gāe jep tāi*). Father understands this. But then he encounters this – himself, his own real life – and his heart sinks (*jaihāi*), and he is full of regret (*siadāi*) and worry (*kangwon*). These books are only principles (*lakthān*). Reality is very different.”

I said, “How did you know that he couldn’t take the news? Did his studying these books ever make you think maybe he could handle it?”

Sak shook his head. “We’re his family. We are very close to him. We just knew.”

There was nothing in Nanban’s demographics or his history as a meditator that could be used to decide what effect knowledge would have on him. It required someone close to him to decide, someone who knew the intricacies of his personality and his mind. Nanban’s doctor, by telling him his diagnosis, had stepped outside the bounds of his knowledge and into the knowledge realm of Nanban’s closest family. And this overstepping of bounds was fatal.

The ethical framework in the first phase of dying in Northern Thailand rests on a principle of giving life by giving heart power. But the way to give heart power cannot rely on a principle – it must be decided case-by-case. This decision must be made by family members, who intimately know the level of mind of the patient.

This fact underlies the conflicts that have arisen in Kiang’s room. The sign on Kiang’s wall declares that she is a “patient,” and thus that she is the same as all other patients. Her “right” to know her diagnosis, according to the sign, does not depend on the specifics of her case. And the sign says nothing about her family, which is not an individual that can have a “right.” But in the first ethical framework inhabiting Kiang’s room – a framework about giving life via heart power – the effect of knowledge is case-dependent, and the power to tell or conceal the truth lies with the family. In this framework, Kiang is not a separate individual with a right to the truth, she is an integral part of a family economy, engaged in the exchange of life and heart power. Truth is not the governing principle of the framework, the individual is not the relevant subject of the

framework, and rights are not an appropriate logic to it. And so the frameworks of the sign and of giving life come into conflict in Kiang's room.

## **Performing Heart Power and the Gymnastics of Secrecy**

Pheuak's family had the most heart power of any family I met. Her grandfather, Mahu, who was dying of rectal cancer, was jolly and silly and made everyone around him laugh. He had a colostomy bag draining his bowels to the outside because of the obstruction of his rectum, and Pheuak had to change and clean the bag for him every day. He laughed and told everyone who came to visit that she was his nurse and that she was so good at it. She slept in the room with him every night, next to his bed, so he could fall asleep holding her hand. And when he would awake in the night, she would adjust his pillows or give him water or change his bag.

Mahu did not know that he had rectal cancer. Everyone told him he had an 'intestine obstruction.' And they told him that the pain everywhere in his body was from gout.

When Mahu and Pheuak visited the doctor, the doctor greeted them, chatted with Mahu about his symptoms briefly, and then asked Mahu if he would leave the room so that the doctor could speak directly to his granddaughter Pheuak. Mahu shakily stood up with his cane and went to the door. At the threshold, he turned around, looking suspicious, feisty as ever, and asked, "why do you want to talk without me? Is it bad?"

"Don't worry, no!" said the doctor. "You'll get rid of this disease, don't worry. We don't want to bother you with the details of care and medications and such..."

Mahu hovered on the threshold, continuing to look suspicious for a moment, and then burst into his disarming smile, "Good! Because I don't like details! Ha ha ha!" And he went outside.

Whenever I interviewed Mahu, he spent most of his time talking about how good he felt in his heart. “I am in pain, and sometimes I am dizzy dizzy! But I have so much heart power because of my granddaughter, she takes such good care of me!” Often, he would seem to misunderstand a question, such as “what do you know about your disease?” and answer instead, “I have so much heart power. I am so happy!”

After many visits, we all sat together one day in Pheuak and Mahu’s living room. We talked about various things, none of them death or cancer, of course. Mahu had a group of old friends that rode bicycles from village to village visiting with and heckling neighbors. He also liked to feed the chickens and trim the trees around the house. But now Pheuak wouldn’t let him do any of those things because of his illness. “But it doesn’t matter,” he was quick to say, “I can sweep the yard, that is enough for me to keep my heart power up.”

Sitting next to me in the room with Mahu was Tom Tem, my research colleague who was there helping translate Mahu’s Northern Thai into Central Thai. She said “well, Mr. Mahu, we would like to go see the village temple, so I think we will go for a walk. Do you mind if we leave you here?” We always needed an excuse to get away to talk with Pheuak about what was really happening with her grandfather’s heart and body.

Mahu looked suspicious suddenly. He pointed at me: “He’s already seen the temple! You just want to get away so you can talk without me!” There was an awkward silence, and then he burst into his unbridled giggle, “Ha ha! Go and have fun! I need a nap anyway...”

Pheuak’s desire and duty as a granddaughter was to pay back a debt of life to Mahu for the life given to her. In order to do this, she spent her days filling him up with

heart power. Part of this filling of heart power involved concealing from him the truth of his diagnosis and prognosis.

Mahu's role, in turn, as the loving and appreciative grandfather, was to perform both life and heart power for everyone to see. We were made to understand in everything that he said that his spirits were high, he was fighting for life, and he was thankful for the care he was receiving.

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I spent a week at the only official 'hospice' in Thailand, at the National Cancer Center outside of Bangkok. The hospice ward consisted of twenty beds, cordoned off in a separate section of the hospital. It was run by two interns, recent medical graduates who had been randomly assigned there for government service to pay back their medical school education. They both wanted to be radiologists, and were clearly depressed at being stuck for a year having to talk to dying patients.

Walking around their ward, I asked one quietly, "so everyone here knows that they are dying..."

The intern said, "It depends. Actually most of them don't know."

I looked at her, confused. This was the only 'hospice' in Thailand. "And do they know that they have cancer?" I asked.

She thought for a minute, and said, "I think about 50% know."

I looked more incredulous. "But we're at the National Cancer Institute... the word Cancer is written in big letters on the side of the hospital!"

She paused for a moment and then said, “well... you ask ‘do they know?’ What is it to know? They know and they don’t know. They know and they don’t want to know. We don’t tell them. They don’t ask. We give them heart power.”

Sitting later at a restaurant with American friends, I told this story, and someone chimed in, “that’s ridiculous! They either know or they don’t.”

“Have you ever half known something? And not let it into your heart?” I asked this friend, and knowing her life, I continued, “like when did you first know that you wanted to leave your boyfriend?”

She thought for a moment, and said, “You’re right, I sort of knew, and then I waited because I didn’t want to know, and that was bad, because I knew I wanted to leave, but I was still in it. I was carrying it around with me like a weight, but I couldn’t look at it. Then one day I really knew, and so I left.”

Does Mahu “know” that he has cancer and that he is dying? Or does he both “know” and “not know”?

My American friend’s version of “sort of knowing” is somewhat close to the kind of “not knowing” experienced by dying patients in Northern Thailand, but not quite exact. It is more that “knowledge” simply isn’t what is at stake.<sup>11</sup> The central question for Pheuak and for Mahu is not: “does he know what he has?” It is “does he have heart power?” The issue of knowledge is skirted by everyone involved. But the issue of heart power is performed front and center.

“Do you think your grandfather knows what he has?” I asked Pheuak once.

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<sup>11</sup> This line of inquiry about the importance of truth in a hierarchy of values owes a great debt to Vincanne Adams (Adams 2005, Adams et al. 2005).

“Well... I don’t know,” she said. “Maybe. Yes. No. I’m not sure. He... he has heart power.”

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When I first met Mr. Meuandak, my introduction to him was the same as with many patients before him, “His daughter wants to make sure that no one tells him what he has,” warned the nurse. “His daughter is from Bangkok, she left today. His wife doesn’t know either.”

When Tom Tem and I first sat down with Mr. Meuandak and his wife at their very small rural home, I felt extraordinarily awkward – the first time I had felt that way in months of fieldwork. A silence sat in the room. Mr. Meuandak and his wife were overly polite about my presence. I had made a mistake and come directly from the hospital, in my nice business-casual outfit. I sat in tailored pants on the floor of their very impoverished house. Everything was going wrong. Mr. Meuandak looked pained and was straining to pay attention to my presence, probably looking at me through a haze of pain from his quickly evolving gastric cancer. The phone rang, and Mr. Meuandak’s wife answered. “Allo?” she said in Northern Thai dialect, “we are meeting with a foreign (*farang*) doctor<sup>12</sup> doing research at the hospital.” I had picked up enough Northern Thai to follow most conversations. She reached out and handed me the phone, “it’s my daughter, she would like to speak with you,” she said.

I took the phone and introduced myself.

“Thank you for coming,” said the daughter over the phone in Central Thai, “I just wanted to make sure you don’t tell my father what he has. He will lose all his heart power and will get worse.”

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<sup>12</sup> Despite my repeated explanations otherwise, I was always called ‘doctor.’ Eventually, I gave up.

“Ok, thank you,” I said, trying to think of how to respond in a way that would not reveal what the daughter had said. “I am glad to help. I’m here to give heart power to everyone.” This setup was no shock to me – I had seen extraordinary gymnastics to keep a diagnosis from a patient. I had seen hand signals pass between relatives and doctors during a short patient visit. I had seen whispered conversations in the hall. I had seen doctors ask patients, like Pheuak’s grandfather, to leave the room so the family could talk alone.

When I hung up, the void of awkwardness was still in the room, and both Mr. Meundang and his wife looked at me expectantly for my first question. I took a medical tack first. “I don’t know much about your case. Can you explain a little about your illness to me?” I asked. I was expecting him to talk about symptoms, and the first time he went to the hospital. If he mentioned anything about the disease, I expected him to say “I am stomach,” the way the Thai language allows for vagueness in explaining diagnoses. All patients are told something about what they have, and it is usually just the organ that is involved. Sometimes it goes as far as a word like “obstruction” or even “mass.” The language allows for many layers of partial truths to obscure a fact that would cause someone to lose heart power.

Instead, Mr. Meundang shocked me by saying, “I have stomach cancer, stage four.”

His wife jumped in quickly, “please don’t tell our daughter that we know what he has. She will lose heart power, and we want her to have as much heart power as she can right now. She lives so far away.”

I sat stunned for a moment. Then I asked, “Who told you what disease you have?”

“The first doctor,” Meuandak said. “I wanted to know because we live here all alone. We have to make decisions.” And for a moment, the awkward formality was pierced as he looked across at his wife and then at me, as if to say, *what if she was the only one who knew and we were all alone? It would be too hard on her!*

After that, the awkwardness returned, and soon Tom Tem and I excused ourselves to go. We returned many times, and each time, the same awkwardness remained. But once, when Meuandak went inside to use the toilet, his wife quickly whispered a rapid, hushed flood of words to Tom Tem in Northern dialect. I didn’t catch them, but knew something important had happened. Meuandak returned, and we all continued on in our usual awkward silence. On our ride home, Tom Tem explained, “she said so much in that moment! She said that Meuandak is out of heart power, and has talked about wanting to die. She is worried that his despair might kill him.”

Everyone in Meuandak’s family knew that he had cancer, but they couldn’t talk about it because they all needed to perform heart power for one another. Even with knowledge, everyone in the family knowing disease and prognosis, the nature of knowledge was still ambivalent. Knowing his diagnosis was “killing” Meuandak. And in their desperation to stay afloat, everyone in the family was performing heart power: Meuandak’s wife by lying to their daughter and whispering to us when he was in the toilet; Meuandak’s daughter by keeping the diagnosis from her father; and Meuandak, by trying his hardest to keep his spirits up while we were there, despite his cloud of pain.

Even though Meandakan “knew” his diagnosis, performing ignorance was still a central part of performing heart power. Meandakan’s family was impelled to give him life, to pay back their debt of life to him. In order to do so, they wanted to make sure that his store of heart power was replete. Meandakan, in turn, needed to show that he was full of heart power, and feigning ignorance was central to this.

### **The Theater of Exchange: Who is it for?**

It was dusk, and I rode my motorcycle through rice fields, alit with the red evening sun. I arrived at Fawng's traditional teak house, and I was ushered up to the second floor to sit by the old woman's side. Fawng was already at the edge of death. Her breath was a death rattle. The broken-down lining of her airways had already begun to block the passage of air, and her tongue, weak with exhaustion, was moving in and out of her throat with a sickening slurping noise. Fawng's daughter, Jantip, sat with a small sponge and wiped it back-and-forth along her mother's dry lips. Fawng's lips closed down into a smile upon the sponge in response to the wetness. With each of these smiles, Jantip looked up at me and at her siblings in expectant joy. Watching her care for her mother, hinging on her every motion, on her every expression, I could think only of the word "close." They were linked at every juncture, in emotion, in sensation, in touch. There was no breath, no twitch, no pain that Jantip did not also feel alongside her mother, as if their beings were tethered. It was more than care, it was a mutual constitution. Jantip sat by her mother's side, so close to her that she almost *was* her. I sat, speechless and enthralled.

Fawng's son, Thaen, came and sat next to me. He was a prominent military officer, and had trained in the United States, and his English was excellent. He pointed to the tall oxygen machine leaning against the wall, attached by a canula to Fawng's nose. He began to whisper a monologue in English to me:

Who is that machine for? Is it for grandmother (*yai*)? No. It is for my sisters. *Yai* will die of not enough air anyway. The tube only makes it take longer. And when my sisters feed *Yai*, is that for her? No. She doesn't want food any more. She can barely swallow. She is not conscious enough to want food. It is for my sisters, who want to feed her. Here it is not like in your country. I have read in

the papers, and I remember from my time in the US how you think. You do things because it is what the patient wants. Here, we do things because we love *Yai*, because we want to care for her. My sisters, they do not think about *Yai's* feelings or her suffering, they think about their sorrow and their debt to her. I wanted to let her go without any machines or anything, because I think maybe she will suffer less. I think this way from my time abroad. I am the oldest son, and it is my decision. *Yai* has so many children, so I have to decide. But my sisters want these things so much, so I agree with them for their own heart power (*kamlang jai*). It is like that woman *Juling*, the girl who went to the South to teach, even though her parents didn't want her to. She was surrounded by terrorists who beat her in the head until she was almost dead. The Queen kept her alive in the hospital for many months, six months, even though she was suffering and only alive on machines. Did the Queen keep her alive for her? No. She kept her alive to show the Thai people that she will protect them against terrorists at all costs. She kept *Juling* alive to give the people *kamlang jai*.

Thaen was not upset about this state of things. His voice was resigned and gentle, trying to explain unfamiliar things to a Westerner. Nonetheless, there was a critique of his sisters not thinking of Fawng's "feelings and suffering." Sitting there, watching Jantip care for her mother, this explanation didn't feel right. After listening to Thaen's explanation of the scene I was watching unfold before me, I watched Jantip take a spoonful of blended, boiled rice and lower it slowly, infinitely carefully (time almost stopping for a moment) into her mother's mouth, and then I watched the slightest expression, a registering of taste, pass over Fawng's face, and Jantip's face followed these flickers on her mother's face almost as if it were her own face. They were so close in this experience that they were almost one. Thaen's explanation of what was happening had been in English, and Jantip had not understood, but I got the feeling that she wouldn't have cared. Her whole being was absorbed in her mother's being.

Thaen raised the question: who is the debt of life *for*? Is it *for* the dying person, or is it *for* the person giving it? Is it selfish or altruistic?

I felt a beginning of the answer to this question in the tight connection between Jantip and her mother. Could one really say that what was going on at the interface between them was really *for* either one?<sup>13</sup>

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One afternoon, early in my fieldwork, I sat in a café with a nursing student friend of mine. She told me about a case she was working on. An elderly man came into the hospital. He didn't want to come into the hospital, but his son said, "no way... we're taking you to the hospital." At the hospital, the old man said often, "I want to go home, I don't need any of this (treatment)." But his son always told the doctors "we are treating until the very end." One day, the old man's heart faltered, and the medical staff gave him cardiopulmonary resuscitation. He regained consciousness briefly, and they decided to take him into surgery. After surgery, his heart faltered again, and the medical staff gave cardiopulmonary resuscitation again, and then the man spent several days on a mechanical respirator in the intensive care unit before his son decided to take him home to die.

"Wow," I said to my friend after the story. "That is so confusing to me... the patient clearly expressed his wishes and everyone went against what he wanted!"

She rolled her eyes at me. "You think so like a foreigner (*farang*)! The part (*suan*) of a father is to say 'don't worry about me, I am fine, I am ready for whatever comes,' and the part of a son is to say 'no way, we're doing everything until the end.' They both do the right thing, and they both get merit." I thought about her use of the

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<sup>13</sup> For a beautiful exploration of fusion of self and other in care giving, see (Aulino 2008a).

word ‘part,’ which invoked a play – the theater of the family, or more accurately a theater of exchange, of paying back the debt of life. Everyone maximizes the exchange, each by playing her part.

The first phase of dying in Northern Thailand is governed by an imperative to give life. Relatives give life by giving flesh, blood and breath, and by giving heart power. Dying patients, in turn, perform heart power, including the state of ignorance required to keep their heart up. Simultaneously, patients graciously accept the gifts that are given to them. The part of a patient is to figure out how to move toward the end of life without thinking too much, and to appear to everyone around to be heartfully ignorant.

It is through this theatre of exchanging life that the small dance at Kiang’s bedside comes to light. Jae gives her mother life and heart power, and despite a gentle nudge with the phrase “I don’t think this disease is going away,” Kiang performs her ignorance for Jae. The sign on Kiang’s wall declaring her right to know contributes nothing to this fragile balance. Instead, the sign hovers as a destabilizing and dangerous threat to the play being enacted below. And so it is ignored by everyone involved.

### **Karmic Duty: *Jao Kam Nāi Wāen* and Acceptance**

My nursing student friend said that the part (*suan*) of her patient, dying in the hospital, was to accept his illness and perform heart power for his loved ones. Accepting his illness, however, did not mean knowing the specifics of his disease and prognosis, which would bring the inevitability of impending death into the open and destroy the family's performance of heart power. Instead, the performance required ignorance.

Mahu's role in his family was to constantly show Pheuak that he was full of heart power – to be jolly even about the changing of his colostomy bag and about still being able to sweep the yard. Mahu accepted his situation without needing to know the truth about it.

When I asked Mahu about how he dealt with being sick, he said, “Ah, it is easy. My disease is a *jao kam nāi wāen*.” I did not understand this word, and so I did not catch it the first time. I took the word *kam*, karma, at its face value. I thought Mahu meant that his disease was fated, that it was pre-determined by an accumulation of many past deeds, both good and bad. But how, exactly, did that help with acceptance? How could it produce such a jolly demeanor about being ill?

Later, pouring over transcripts from my interviews, I noticed that the word *jao kam nāi wāen* appeared everywhere, and I asked Tom Tem about it. It took a long morning of examples for me to understand it. *Jao* means “owner” or “master,” someone who reigns over something. *Kam* means karma, usually implying the residual consequences of past actions.<sup>14</sup> *Nāi wāen* means “duty officer,” literally an official who exacts an owed toll. By *jao kam nāi wāen*, Mahu was referring to some living being that

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<sup>14</sup> In precise Buddhist scholarship, *kam* means action, but in common usage it refers to the whole system by which action gives rise to consequence, and often only to the results of action.

had unfinished business with him, someone that he had acted upon to generate karma, and who was now returning to exact a payment for that past action.

“My whole life,” explained Mahu, “I was a buffalo farmer. I leashed buffaloes with rings through their noses. Last week, when I went into the hospital, I had an oxygen tube, and they put it in my nose just like a ring. When they put it in, it made me sneeze and cough just like the buffaloes used to sneeze and cough. And when they took it out, there was still a tube through my nose into my stomach [a nasogastric tube], and when I turned my head, it would pull on me just like I pulled on buffaloes.

“Also, I used to ride the buffaloes. And now, my legs are bowed outward...” He stood up to show us how he stood with his knees pointed out to the sides, like he was permanently astride a buffalo. “Now, my knees and hips hurt. The buffalo is still my *jao kam nāi wāen*.” In this life, and likely in past lives, too, Mahu treated buffaloes in a way that left a residue of unfinished business, and now the buffaloes have returned to exact a toll, either actively as spirits in the present, or passively as a residual force that is inherited down through time and makes Mahu have an illness that requires him to be leashed by the nose.

Mali, who knew her diagnosis and meditated for heart power, talked about her pancreatic tumor itself as a *jao kam nāi wāen*. It was a living being come to work out an old relationship with her. She explained:

I have always taken care of myself, eaten healthy food, never smoked. So I know that this tumor must be some old karma (*kam*). I must accept this, and as soon as I accept it, I relax, I let go into it and stop suffering. The tumor is here because it is suffering, and it thinks that this suffering is because of something I have done. So I cannot be angry at the tumor. If I am angry, then I will harm it more, and it will grow and gnaw at me like an angry little dog. Even if I go to the doctor and have her cut out the tumor, I will still die, and so why would I want to hurt the tumor? It would just bring more bad consequences

(*wibākkam*). So instead, I meditate and send loving kindness (*mētta*) to the tumor and ask its forgiveness (*ahōsikam*). Forgiveness is letting go of all of the actions (*kratham*) and consequences (*krathop*) between people, so that the heart can be free. If we do not forgive, and if we cannot convince the *jao kam nāi wāen* to forgive us, to decrease the punishment (*yōk thōt*), our life will stick at that point, and we will suffer and hurt there. And we will not eliminate our residual karmic duty (*mot kam mot wāen*).

*Wāen kam*, to do one's duty to the residual effects of one's past karma, is a process of facing, trying to fix, and trying to let go of what has been built up to this point. It is not knowable how long this will take, but all one can do is relate positively to the negative things that come, and try not to build new negativity with them. A disease is not only an opportunity – it is an entity that needs to be related to, a relationship with an unresolved history that needs to be resolved.

Mahu says that it is easy to accept his illness because it is his *jao kam nāi wāen*. It is not an abstract punishment that needs to be endured. It is a chance to say that he is sorry to the buffalo that he rode his whole life. Without the illness, he would not have this chance, and the unresolved consequences of his past actions would persist. Mali does not know so precisely what her *jao kam nāi wāen* needs from her or how its grievance was developed. So she sits and asks for forgiveness from her tumor for whatever she might have done to it. She then expands her meditation outward and asks for forgiveness from any other *jao kam nāi wāen* that might be out there. The tumor is her chance to forgive and be forgiven for all of her past misdoings.<sup>15</sup>

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<sup>15</sup> Technically, as many of my participants explained, a *jao kam nāi wāen* might be positive, some living being that has come to ask forgiveness for a wrong done, or to return a gift. Mali talked about letting go of such things, too, to try to eliminate all residual *kam*, to have a free mind and not be reborn. But most people talked about *jao kam nāi wāen* only in the negative, and many dictionaries only translate it as “curse” or “ill fortune” or “enemies from a former life...” But as Tom Tem said, “I will probably be a *jao kam nāi wāen* for you, boss, because I will want to repay you for everything you have taught me,” and I agreed that I would come back to do the same for her. We had a moment acknowledging that we were bad Buddhists, pleased for it to be for such a good reason.

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The first interval of dying in Northern Thailand relies on an ethical framework of giving life. The way to give life is partly to give flesh, blood and breath, but mostly to ensure that the dying person is replete with heart power. For patients with a certain level of mind, knowledge can destroy heart power, and so families and patients engage in a theater of deception and a performance of heart power for one another. In this theater, the role of the dying person is to receive the life given, to pretend and craft ignorance, and to accept suffering as an opportunity to eliminate the residual effects of past actions. In this ethical framework, everyone's actions and knowledge are linked, so that decisions and their consequences affect a family web, all engaged in a theatre of exchange, paying back debts of life.

Understanding this framework comes part of the way to understanding the dynamics in Kiang's room. It explains why Jae would ask me to speak English around her mother. And it explains why Jae would say that her mother's right to know her diagnosis is "a right to worry in her last days" and "not a right I want for my mother." But many other things about Kiang's room remain obscure. Why, for example, does Kiang say, "I don't think this disease is going away," followed quickly by, "I want to go home"? And why is Jae's response to this statement so dramatic?

The interaction between Jae and her mother contains a tension, a tension that arises from competing frameworks for what to do about dying. For some reason, by the time I sit in Kiang's hospital room with Jae, Kiang is not performing heart power for her daughter anymore. She has begun to slip in her performance of ignorance. Why? What

has pushed her, at this moment in her hospital room, to start pulling apart the theatre of giving life?

The answer to this question lies in the understanding of a second ethical framework that inhabits Kiang's room. Its core logic is not about giving life, but about place, about being at home at the moment of death. This framework is in tension with the other frameworks inhabiting Kiang's room: it is in tension with Nurse Ampha's hope that Kiang will experience more than a last moment of death; and it is in tension with Jae's imperative to give her mother life at the hospital. This last tension drives Jae to argue with her mother, to persuade her to stop talking about going home.

The second ethical framework governing dying in Northern Thailand is about place, about dying at home. And it is also about time, about a very short "last stage of life" (*wara sutthāi khāwng chīwit*), usually after a patient has lost consciousness and is at death's door. Why does this short period of time require a different ethical framework? How do families and dying patients transition between the frameworks? And what happens to this second framework when new frameworks arrive in Kiang's room?

## **Chapter Two: Place, Spirits, Technology and the Moment of Death**

The first phase of dying in Northern Thailand extends from diagnosis to the last hours of life and involves family members paying down a debt of life. The method for paying the debt of life primarily involves giving heart power, and the way to give heart power is unique to each individual. In this phase of dying, families and patients perform a play, a theater in which families give life and patients perform heart power and try to relate positively to their illness.

In the last hours or day of life – what on my first day was called “the last interval of life” – a second phase begins that is governed by an imperative to maximize the movement of the dying person’s spirit to an optimal rebirth. This phase is dominated by a logic of both place and time. The moment of death, the last breath, must occur at home to ensure an effective and safe transition to rebirth.

Because giving life is maximized in the hospital, and dying is best at home, the two phases of dying create a tension. And because death is seen as only a moment in time, this second phase of dying is in tension with concepts arriving in Kiang’s hospital room – with Nurse Ampha’s hope that Kiang will use the experience of dying to hone her mind, and with the sign on Kiang’s wall, which hopes that Kiang will use the end of her life to exercise her right to self-determination.

## The Importance of Place

Tawo knew that he was dying. No one spoke of this fact around him, not the nurses caring for him in the intensive care unit, not his sons, not his daughter-in-law Nai who was a nurse in the internal medicine ward next door to the ICU. And especially not his youngest son, Loek, who was the most eager to give him heart power and convince him that he would live.

Tawo's organs were failing. He was 73. His liver began to fail years ago, despite never having drunk much alcohol. He was always fussy about discomfort, and through his middle age, he bought village medications whenever he experienced the slightest symptom. His favorite was bird's nest,<sup>16</sup> which increased his overall vitality and cured many little problems. But among the other village medications were steroids and other strong concoctions, and these probably destroyed his liver. But other organs had begun to fail, too. He had congestive heart failure and an arrhythmia in his heart. His kidneys had been on a slow march to failure, and they were no longer cleaning his blood, so twice a week a dialysis machine cleaned his blood for him. After dialysis, his symptoms calmed down, but in between cleanings, he teetered on the edge of meltdown.

At home, Loek took care of his father. Nai, Loek's wife, said that Loek had a lot of *phūkphan*, affection and duty, with his father. Nai had less *phūkphan* with her father-in-law, and had no debt of life to him, and her experience in the hospital and her recent trainings in palliative care made her think that it might have been best to let Tawo "go

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<sup>16</sup> Bird's nest is a Chinese herbal medicine and cuisine delicacy, composed of the inner linings of the nests of cave swiftlets found originally in Malaysian Borneo and Southern Thailand (genera *Aerodramus*, *Hydrochous*, *Schoutedenapus* and *Collocalia*). The swiftlets form the nests by secreting a layer of modified saliva, which hardens into a protective lining for the nest. Bird's nest is widely consumed and available in Thailand. Behind every 7-11 checkout counter in Thailand are special stores of three canonical expensive items: whiskey, cigarettes, and bird's nest.

peacefully.” But Loek was not ready, and was adamant that they treat his father as far as possible. “My father gave me life,” he said, “I need to give it back.”

The first time I met the family, I stood first with Tawo alone in the ICU. He mouthed toothless words to me and smiled a kind, grandfatherly smile. After a moment, his son Loek came into the room, and the room lit up with care. At his father’s side, Loek fed Tawo gently out of a jar of bird’s nest, leaning over to listen to his father’s requests, responding in a way that would give his father heart power. Over many weeks getting to know Loek, I loved watching his joy at caring for his father.

Tawo knew that he was dying, and he was terrified. He was not terrified of dying, exactly. He was terrified of dying *in the hospital*. He was terrified of a bad death, and the hospital would be a bad place to die. He wanted to go home. At night, he wouldn’t let the nurses turn out the lights. At first, they thought he might be scared of the ghosts that many patients see roaming the hospital at night. But really he felt that if it was dark, he might fall asleep, and if he fell asleep, he might not wake up, and he needed to stay awake, to stay alive, to make it home to die. In the ICU, he pulled out his endotracheal tube and moaned, and the nurses came rushing in, and he said “I want to go home. I want to die at home.”

After a round of dialysis, they moved him to the regular ward next door, where his daughter-in-law Nai could watch over him. I went to visit him there. We locked eyes and I held his hand. Then he grabbed my hand and held it to his flank, which felt hard enough that I looked underneath to see if there was a piece of plastic or something surgical there, but it was just his hard ribs with no body fat, and his hardened skin from the kidney and liver disease. He pulled me close so I could hear his voice, which was

still soft from the damage to his vocal chords caused by the endotracheal tubes that had been repeatedly put into his lungs.

“I need bird’s nest,” he said with urgency.

I nodded gently.

He shook his head as though I didn’t understand at all. Now his voice was shaking with panic, and his eyes were wide. “Almost dead, almost dead!” he said. “I need bird’s nest. I’m dying.”

The nurses had told me that Tawo didn’t want to die here, but I was still shocked to hear him say so this directly, this urgently.

“Are you afraid?” I asked, holding his hand again.

He shook his head, “No, no no. I want to go home. Please get me some bird’s nest!”

I was still unsure about what was going on. “Do you want bird’s nest because you’re hungry, or because it’s medicine?” I asked, so sad to see the fear in his eyes and in the grip of his hand.

“Almost dead!” he whisper-shouted, urgent, pulling on my hand, pointing to a patient in the bed next to his, who was strapped into machines, unconscious, his body rising and twisting inhumanly with the artificial life support. “I’m going to die, I need to get better to make it home.”

“Okay,” I said, thinking quickly, swept up into his panic. Doesn’t a patient know when he’s dying? Who else could know better? “I’ll go across the street to 7-11,” I said, “and get you some bird’s nest.”

“No!” he whisper-shouted, and grabbed my arm. “I’ll die! Don’t go! There’s no time!” Then he began to weep, sobs wracking his whole frail, hardened body.

I felt a rush of tears come to my eyes as I watched his fear, and I held his hand, which squeezed mine painfully. After a moment, I said, “I want to stay with you, but I also want to go get some bird’s nest. What do you think is more important?”

After a moment, he stopped crying, looked at me and then nodded bravely and said, “Go!”

I told the nurses about his state of panic, and one of them went to sit with him while I rushed across the street to buy a bottle of bird’s nest from 7-11.

When I returned, Tawo’s eldest son (Loek’s older brother) was standing by his father’s bed, feeding Tawo bites of pork leg rice, his favorite food. The son’s body was tense and his face taut, and I thought with a wave of sadness that he was holding his father’s fear in his body and mind. At one point, Tawo nodded off while eating, and his son slapped his face, waking him back up to the world of the living. On waking, Tawo’s eyes filled with sudden fear, and he nodded vigorously as if to say, “I’m still alive, I’m still alive,” convincing himself and his son. Then he paused, looked at his son and said, “I want to go home.”

His son looked despondent. Later, after his father’s death I asked him about the phrase “I want to go home (*yāk klap bān*).” “Dying,” he replied, “has to take place at home. So when someone says ‘I want to go home,’ they mean two things, mixed together. They mean ‘I want to go home,’ but they also mean ‘I want to die, I am ready to die.’ Home is death is home.” So when Tawo said “I want to go home,” his son looked suddenly despondent, because his father was talking about dying. His son was

still engaged in the process of giving his father life, and his father had stopped playing his part in the play, had stopped performing heart power. Everything was falling apart.

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That night, Tawo felt particularly like he was going to die. He was in an open-air ward, with lots of machines ticking and breathing and lights on and nurses bustling around. Nai was not there... she had gone home to sleep. The world was foreign and full of strangers – not like home, where everything was right and familiar and appropriate for dying. Tawo kept nodding off, and the sleep place where he went felt like death and he woke himself each time in terror. He thought about home, about what he used to do at home. He stopped nurses as they passed, and mouthed to them, “I want to go home,” and acted out with his hands the things he wanted to do at home: washing dishes, making food, tying loops of sacred thread (*sāisin*) around his grandchildren’s wrists to bless them. He asked the nurses for his wallet, so he could hold money in his hand to take with him into his next life, in case he died here accidentally in the middle of the night by letting himself fall asleep. But the nurses ignored him and went about changing bed pans and drawing blood.

Tawo realized that the project of getting better to go home was not working, and he guessed that if he got worse, they might take him home to die. He decided that he needed to get worse but not die, so that they would decide to take him home while he was still alive. If he fell asleep, he might die without knowing it. But if he stayed awake and got worse, they might take him home. So he removed his oxygen canula from his nose and wrapped the cord around his neck, pulling tight, trying to cut off his air. But the cord was weak and had no effect. Eventually the nurses saw him and rushed to stop him,

thinking “crazy old man.” They restored the oxygen to its right configuration. Tawo could think of no other strategy, so he went on waiting, trying to stay awake to stay alive.

I sat with Nai, Tawo’s daughter-in-law, at the nursing station while she recounted these events to me. “We’re all realizing,” she said, and I knew by ‘we’ she meant Loek, whose affectionate duty (*phūkphan*) and life debt were the strongest, “that grandfather is almost in the last interval of life. We need to take him home, so he can die at home. Maybe we’ll take him home tomorrow after his dialysis.”

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That night, Tawo went into cardiac arrest and lost consciousness. The doctor on call was nearby and initiated advanced cardiac life support. It took ten minutes to restart Tawo’s heart, and required intubation (life support) to pump his lungs and continuous IV medications to keep his blood pressure up. His ribs were broken and his chest bruised from the cardiopulmonary resuscitation.

The nursing team called Nai and Loek, who rushed to the hospital. They quickly put together a hospital ambulance. They removed Tawo from his respirator machine, and attached a hand-pumped bag to his endotracheal tube, pumping his lungs manually, once every three seconds. Nai did the pumping: squeeze-rest-rest squeeze-rest-rest. They took the IV bag from its metal rack, and held it high while they wheeled him to the ambulance to take him home, all of his medical equipment still attached in mobile form to ensure that he would make it home before taking his last breath.

In the ambulance, they folded money in his hand. The money would ensure that he would have wealth in the next life, and they wanted him to have it on the way home, in case the mobile equipment failed to keep him alive until then. They whispered in his

ear: “*namō, namō, namō,*” the first word of the Homage to the Blessed One. And they narrated to him about landmarks they were passing so that he would know the way home in case his spirit had already begun to separate from his body.

When they reached the house, his heart was still beating, and Nai was still pumping air into his lungs. They sat that way with him for a time, and family members took turns asking Tawo for forgiveness, telling him to let go of any worries he might have about them, telling him to clear his mind and think of the Buddha. Then Nai withdrew the endotracheal tube, and Tawo took his last breath and died.

Later, at the funeral, I asked Loek about how he thought that everything went with his father. That was when he said, “In Thailand, our parents are our holy trees (*rom pō rom sai*), our Gods (*phra jao*). We have to give them everything, to the very end.”

“What do you mean by ‘everything’?” I asked, thinking to myself: *you didn’t give him what he was asking for most, which was to go home.*

He thought for a moment, and then said, “We have to give them life.”

Later, without prompting from me, Nai said, “We are so glad that he was able to be at home when he died.”

“Was he conscious?” I asked, still confused and trying as gently as possible to push on this idea of dying at home. *What did it mean to die at home if he was not awake to know it?*

“He took his last breath there,” said Nai.

At the funeral, they read a four-minute history of Tawo and his illness. It listed his family members, and then said:

Father Tawo was a farmer, and when he was not farming, he sold umbrellas and fans. He worked with honesty, diligence, and perseverance to care for his family. His children

have all raised families and become good people, some government workers and some in private business. At 8:51 am on May 13<sup>th</sup>, Father Tawo passed away peacefully at home from kidney failure. His wife and children made merit (*bamphen guson*) up until the moment [of death]. Father's goodness and love will be wrapped up (*trätreuung*) in our hearts forever.

According to this eulogy, and according to Loek and Nai, Tawo had died “peacefully, at home.” In my foreigner's mind, there seemed to be absolutely nothing peaceful about Tawo's death. Everything seemed to have gone wrong: he was terrified and upset for many days before dying; then his body was thrashed and pumped full of medications simply to keep his heart beating until he got home.

But those around Tawo insisted that all was well. The activities leading up to Tawo's death were summed up as “making merit.” Tawo's sons had given him “everything,” meaning life, until the last possible moment. And then Tawo had “taken his last breath” at home. Everything had gone well.

Why did Mr. Tawo want so badly to go home? Why was he so afraid to die at the hospital? Everyone clearly agreed that he needed to die at home, so much so that they restarted his heart and mobilized his life-support to make sure his last breath was taken at home. Then why was there such a tension between Tawo and his sons, and why did he stay so long at the hospital?

There is the beginning of an ethical framework contained in Nai's seemingly straightforward comment, “grandfather is almost in the last interval of life. We need to take him home, so he can go [die] at home.”

## **The Home: Morality, Comfort and Ceremony**

I am sitting in Fawng's old-style teak house, on the second floor, watching Jantip take care of her mother again, enthralled by the intimacy of the link between them. Fawng's mouth is responding less frequently to the swabs of moisture from Jantip's sponge. Her eyes are closed, and her mouth is sunken in and the death rattle is louder with each passing hour. Fawng has been unconscious, in her "last interval of life," for more than a day now. She is lying on a single-bed mat on the floor. Surrounding her are cloth bags full of clothes, a pile of photographs, some in frames, others stacked in a loose pile. This sum of baggage contains all of Fawng's possessions.

I interrupt Jantip for a moment to ask about the bags. "They are all of grandmother's possessions," she says.

"Are they to take with her into the next life?" I ask.

"No!" she exclaims, "When we die, we can't take anything, not this body, not these things. Except this..." She smiles sheepishly and points to the small wad of bills folded up in Fawng's hand, "but she doesn't take the money with her, just the luck."

"Are the bags of clothes for luck, too?" I ask.

"No. They are so that when mother goes, she will have everything here, and she will not miss things, and so she will not hold anything in her heart. If her heart is stuck to anything at the moment that she goes, she will be reborn with that karma. Everyone should be here, too, so that she is not worried about anyone."

Next to Fawng's head is an ornate silver platter. On the platter are short stem yellow and white flowers and a small silver cup filled with red liquid. The platter is for the forgiveness ceremony (*ahōsikam* or *pongpan*). Earlier in the day, before I arrived,

each of Fawng's children and grandchildren took the platter in their hands, bowed their head over Fawng's chest, and quietly asked her for forgiveness for any wrongs that they had done her during her life. If they could think of specific wrongs, then they spoke about those, like Fawng's son, who went away to work in Bangkok for too long, leaving Fawng at home to worry; or like Fawng's daughter, who fought with her sisters throughout childhood. But Fawng's family was loving and kind, and they hadn't wronged one another in many ways, so mostly they asked forgiveness for generic failings. They also each put a hand on her, or bowed their heads, and told her they loved her, and that she should let go of everything and that she had done so much for them during her life.

"All of this," explained Jantip, "is to have grandmother let go of everything. Her things are here, all of the people are here. And the most important thing is that she is at home, where she spent her whole life. She won't miss anything when she goes. Her mind will be empty, and she will go without being hooked by anything here. She will go peacefully."

"Does she hear the things that people say to her? Does she see these things all around her?" I ask, wondering about the spiritual mechanics of this empty mind that Jantip is crafting in her mother.

"She is unconscious, but her spirit (*winyān*) receives everything. When we make merit for her, the spirit receives it, and her rebirth is better."

That evening, Fawng's breathing slows breath by breath, and her lungs fill with fluid, so that her chest rises periodically through a liquid gurgling. Eventually, the breaths are ten seconds apart. The whole family gathers around her bed, and they begin

to whisper in her ear, “*phuttō, phuttō*” a name of the Buddha, and they tell Fawng to look for the color orange, for the image of flowing robes of a monk who will be waiting for her to lead her to a sacred place. And if Fawng is not hooked by anything in this world, if she lets go of worry, and if she follows the corner of the monk’s robe, her eyes trained downward on the corner of orange cloth, her rebirth will be good.

As she dies, her consciousness completes its separation from her body. This separation has been going on for some time now. Her body is made up of the four elements of physical form (*rūp*) - earth, fire, water and wind. The earth part of her body dies first, the strength draining from her muscles. Then the water goes, giving rise to her death rattle and dry mouth that Jantip has spent hours moistening with a sponge. Then the fire leaves, and the body turns cold to the touch. The last part of her body to be evacuated of consciousness is the breath, the wind. Her breaths slow, further and further apart, and eventually stop.

Fawng will not be reborn right away. In fact, she may not even know that she is dead. But it does not matter, because she is at home, it is comfortable and familiar. Everyone she cares about is near, as are her things. The next five days will consist of rituals, presided by monks, whose purpose is to transfer as much merit as possible to Fawng’s spirit to help with her eventual rebirth. When the monks arrive, Fawng will know from their chanting that she is dead. And she will receive the merit that they and the family make for her.

Fawng’s death is ideal in many ways, and the core of its appropriateness is about its location, about home. Death is envisioned as a short process, a moment. And the contents of Fawng’s mind at the moment of death are paramount. Home is full of

familiar people, things and ceremonies that can ensure appropriate contents in her mind at the moment of death, and thus a good passage to the next life.

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When Bet arrived, after a lifetime of estrangement, at the bedside of her mother, Hawm, to repay her debt of life, she latched on to concrete things she could do to help. She looked at her mother and saw a stranger, and so the kind of intimate care generated by *phūkphan*, by affectionate duty, was impossible between Bet and Hawm. Instead of affection, she provided things. When her mother was hot, and it seemed that ice would help, Bet went out and bought ground ice at the market across from the hospital. She asked the nurses for concrete things she could do to help. She was paying down her debt of life to the mother she did not know.

But on the third day of caring for her mother, Bet coalesced her activities into a single focus: her mother needed to go home. It was the only thing her mother was requesting. In the moment when Hawm looked Bet in the eyes and kissed her for the first time and said “I love you,” she then said, “I want to go home.” Although Bet had no *phūkphan* with her mother, no strings of obligation and connection built between them, Bet felt deep in her gut that her mother needed to go home to die there.

“Why is it so important for her to die there?” I later asked Bet.

“The hospital is not a sacred (*saksit*) place,” she answered. “The home is. It would be bad for her to die here. Her spirit would not be happy.”

I thought about Fawng’s bedside, the piles of clothes in bags, the money in her hand, the ornate silver platter for the forgiveness (*ahōsikam* or *pongpan*) ceremony. I

asked Bet about whether they would do those things at home once her mother arrived, and she nodded in her excited girlish way, “exactly!”

“If your mother died here in the hospital, would you do the same things here?” I asked.

She nodded, but without enthusiasm. “The hospital is not sacred (*saksit*). We would make merit and we would put money in her hand and ask for forgiveness, but the merit would not get to her as well.”

“You mean the same ceremonies have no effect here?” I asked.

“No, they would work,” she said and sat quite for a moment before adding, “but probably only 60%.” Then she paused, and looked around. “This place, the hospital, would not help the ceremonies work.”

We sat together for a moment, and I looked around and saw as if with new eyes some of the unsacred in the space around us. The hospital room was an open ward, and half the patients were on mechanical ventilators. The air was sterile and filled with the beeps and boops of machines. Nurses scuffled around with gloves, wheeling blood-pressure check units to the beds of almost corpse-like patients, strapped as modern cyborgs into the life-machines of medical innovation.

I wasn't sure from her words whether they were a creative way of expressing how the hospital feels or something more general. But it was late, and it felt like time to go, so I let the matter rest.

Bet did manage to get her mother home to die, but I wasn't there. I arrived the next day at the funeral. And feeling emboldened by the general calm and playfulness at the funeral, I asked at a table of relatives about the ceremonies they did by Hawm's

bedside before she died. They placed money in her hand, and they asked for forgiveness, and they made merit at the temple that day.

“Would those things have worked if you had done them at the hospital?” I asked.

“No!” the group responded. When I looked confused, Hawm’s husband leaned over and said, “making merit has to be done at the home or at the temple. Otherwise, it’s just not 100%.”

The logic governing the second phase of dying is about crafting the ideal separation of spirit from body. The most important determinant of this separation is the contents of the mind at the moment of death. But there is also a metaphysical law that governs those contents, a law about transferring merit to the dying spirit. And at the core of that merit transfer is place. Ceremonies conducted at the hospital simply do not work well. Ceremonies conducted at home work much better. Why?

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In his article “Power and Goodness in Thai Symbolic Representations,” Niels Mulder describes the particular concept of ‘power’ in Thailand that has arisen from the fusion of Buddhism and Animism (Mulder 2000). Animism poses the existence of an essentially amoral, intangible conscious power residing in objects and places. A rice field is inhabited by a spirit that animates it, that makes the stalks of rice perk up and grow and live. A person is animated by a *khwan*, which imbues energy and spark and personality. A city is guarded by a spirit that maintains a historical memory of the place and demands things from those who live there.

This animistic power is neither good nor bad. Spirits reside in and dominate certain places, and they have personalities and needs, but they are not judges of moral

good or right. One must simply negotiate with them. Their power can be used to benefit or to harm, and one must have skill – either at pleasing spirits who might be of help, or at calming those that might cause harm. Mulder calls this metaphysical landscape “power” because people view it as an instrumental tool that needs to be wielded and navigated, but that remains unchanged, almost like principles of physics.

Buddhism presents a very different kind of power. “Buddhism,” of course, stands in for many different systems of belief. Mali’s equanimity of mind is not the same “Buddhism” as Fawng’s family’s rituals at the bedside.<sup>17</sup> But according to Mulder, Thai Buddhism in all its forms is based on *moral* power, because it poses the ability to create good or to create evil through the actions of living beings. Monks, through study and through contemplative practice, are able to transcend the natural tendency of the mind to suffer and to cause others to suffer. This is a kind of moral creativity because it changes the balance of good to bad in the thoughts and actions in the world. There is a global store of “goodness”; Buddhism offers a way to increase it through action. “Goodness” is *bun*, or merit – and in most Thais’ understanding of Buddhism, merit can be acquired, accumulated, transferred, lost, spent, and wasted. Monks, and the temples they preside over, are the centers of this moral power and thus they are the greatest generators and storehouses of merit.

In order to clarify his model, Mulder categorizes people and places by the kinds of power they are identified with. In his scheme, women are moral mothers who generate merit and turn homes into centers of moral power (secondary only to temples). Men, on the other hand, leave these moral centers to go out into the world of amoral power, which

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<sup>17</sup> For an attempt to typologize the different species of Buddhism in the Theravada world, see (Spiro 1982) and (Buddhadasa 1956).

they navigate using wisdom and intellect. Their world consists of practical decisions in a landscape of laws – trading stocks, negotiating bureaucracies, and charming the spirits that animate the world into making their actions profitable.

The two worlds of “power,” moral and animistic, are inseparably intertwined. Both forms of power are present everywhere, inseparably mixed and interactive in complex ways. Monks’ moral power can penetrate into the animistic spirit world, cleanse it, and transform it into goodness. Thus a charismatic cult has arisen in the Thai clergy, in which monks use their moral prowess to create amulets that confer luck and protection from the amoral animistic world (Tambiah 1984). Moral goodness is part of the calculus of all events. Nothing is independent of moral law.

Mulder’s scheme, bound up in an era of social science prone to generalized theories, runs into problems because it forces people and places into categories that are broken as often as they are followed. But he poses a simple question: is the power that resides in a place moral or amoral? And he identifies the home as a particularly important place for answering this question. This inquiry into the nature of power that resides in the home provides essential insight into Bet’s dramatic insistence on getting her mother home to die, and on the insistence that ceremonies outside of the home “just aren’t 100%.”

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When I first talked to Janpeng, whose mother was dying of lung cancer, she said that she wanted her mother to be at the hospital until the very end, including her death. When she said this, I was surprised because I had yet to meet someone who didn’t place a premium on dying at home. But I said nothing: Janpeng and I were sitting on a plastic

couch in the hospital hall crying because of how much sorrow Janpeng was holding, all by herself, the burden of her mother's care and her mother's death on her shoulders. There was no one to help her make decisions. She left her job at lunch every day, and drove out to the hospital to spend a half-hour with her mother.

The next time I saw her, Janpeng looked even more strained. She fidgeted with brochures and books of Buddhist sermons that were laid out on the hall table between plastic couches. I asked what was on her mind.

"I can't decide whether to take mother home or not," she said. "I think she should be here, but I just can't stop thinking that I'm making the wrong decision. What do you think?"

I asked Janpeng why she wanted her mother at the hospital.

"The hospital has a lot of power (*mī amnāt*)," she said. "It has equipment, it has knowledge, it has doctors. My mother gave me life, and I want her to be close to the doctor so he can take care of her."

"So why are you confused... why do you want to take her home?" I asked.

"The hospital is missing so many important things for the... the last interval of life," she said. "There are no monks here. They come to visit, but their prayers don't work well. A monk came to visit mother last week, and he said he would chant, but that it wouldn't help much. She needs to go home or to the temple. And all of mother's things are at home. It is where she grew up, it is familiar and comfortable. It is safe at home."

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Janpeng's word, safe, seemed simple enough to me at the time. It was only later, after Janpeng's mother's funeral, that I got confused about it. Janpeng wanted her mother near the doctor because it was safe. But she also wanted her at home because it was safe. These were not the same kind of safety. And the hospital also seemed dangerous in some way. Tawo was not terrified of dying, but of dying *in the hospital*. Clearly, hospital and home were nodes in some metaphysical landscape at the heart of the ethical framework governing decisions about the second phase of dying in Northern Thailand.

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One patient that I followed was in a general ward and on a very busy week at the hospital. He was on a mechanical ventilator and receiving dialysis. He was in pain from the tube in his throat, but when his family came to visit he was visibly happy, and when they asked how he was doing he seemed full of heart power. He was getting better, too, and one evening they withdrew the breathing tube, and he was able to keep his breathing up without it. The next morning, however, when I came into the room, the family was clearly upset, huddled in a tight knot, and there was tension in the air between them and the nurse, who came to take his blood pressure. Back at the nurses' station, I asked what was going on.

"The patient thinks his bed is haunted by a constricting ghost (*pī am*)," explained the nurse. "Last night, a ghost sat on his chest and he couldn't breathe, and so now they want a new bed, but there are no free beds. We can't move someone else into his bed either."

"*Is his bed haunted by a ghost?*" I asked.

She laughed at my question, and then shook her head in a clear no. But then she paused to think and said, “well, I don’t know, maybe. I’ve never seen a ghost in this hospital, but maybe.” She seemed not inclined to claim the existence of ghosts, but she did not seem inclined to claim their non-existence either.

“Could a monk come purify the bed?” I asked.

She shook her head, “I mentioned that, and they didn’t agree. They said, ‘so many people have died here, how could the monk succeed?’” Apparently the hospital was so full of ghosts it was refractory to the moral power of a single monk.

I thought of a moment several months before, riding to a rural province to work as a medical student in a small community hospital. Three other medical students and I were riding through rice fields on the way to our assignment. One turned to me and asked, “are you afraid?”

“Afraid of what?” I asked, thinking he must be referring to my incomplete medical training.

“Afraid of ghosts!” he said. “These hospitals are full of ghosts, especially out in the countryside. They like to haunt new people who come, too. It’s unsafe.” I looked around to the other medical students and they nodded in confirmation, not so much that there really would be ghosts at the hospital, but that the medical student wasn’t pulling my leg and that he genuinely believed there might be ghosts.

Later, when we were sitting in our beds in the hospital dormitory, he showed me a photograph on his computer:



Figure 1. A medical student's proof of ghosts' affinity for hospitals.

My medical student friend smiled knowingly when I saw the photograph, as though it was proof of the existence of ghosts. He added that most photos of ghosts are in hospitals, because that is where ghosts are often closest at hand.

“Is this real?” I asked, wondering what kind of argument he was making. We were sitting on a rickety bed in a dilapidated old dormitory outside a rural hospital where the word “resident” still held its original meaning of resident doctors – recent medical school graduates both living at and running a hospital for a huge county of impoverished villagers. The hospital was surrounded by mountains and jungles, and for a moment I

had an eerie ethnographic dizziness thinking of the poor resident staff, living in a place haunted by ghosts.

“I don’t know if it’s real or where it comes from,” my student friend answered, but he did not seem concerned. Belief was more practical than that. To me, his admission that it might be fake seemed good proof that he wasn’t teasing. And by this point, I had had conversations about ghosts with nearly everyone I knew in Thailand, so I knew that my medical school friend was no outlier in his beliefs.

“Some people believe in ghosts, and others aren’t sure,” he explained, “but everyone is afraid of them.” He smiled a mischievous, knowing smile. “I have seen them twice. First, when I was a kid, I saw one in the woods. And then I saw one in the hospital in the pharmaceutical dispensary at night.”

An internet search for the words “hospital” and “ghost” in Thai brought up the same photograph that the medical student showed me. It is a blown-up and cleaned-up portion of a poster for the Thai horror film *hian* (English titles: “The Unborn” and “The Mother”), a movie about a pregnant woman who is brought to the hospital after being beaten. At the hospital, she is haunted by a ghost-child who she thinks is the spirit of her unborn fetus, but turns out to be the spirit of a child who was wrongly murdered and has come back looking for help exacting justice. Thailand is not legendary for high-quality film, but it is legendary for ghost movies, and most ghost movies take place at hospitals. Hospitals are where people die. It is where they die inauspicious deaths that make them hungry and insatiable souls that wander and harm the living.

Like animating spirits (*khwan*), ghosts (*phī*) are a product of the fusion of Buddhism and animism in Thai religion. For some people, death does not initially

produce a freed, disembodied consciousness (*winyān*). Instead it produces a ghost (*phi*) – an intermediate, polluting and dangerous entity. This entity persists for an unknown amount of time before being reborn – possibly until the body of the deceased is disposed permanently by cremation,<sup>18</sup> or possibly longer if the spirit has some unresolved issue or attachment. Ghosts embody the ambiguity and interface between moral and amoral forms of power. A spirit (*winyān*) may become a ghost (*phī*) because of its own unresolved moral issues. Because of this, monks who die of old age are seen to be so pure and good that they cannot spend time as ghosts at all, but move immediately into their next rebirth (Keyes 1982). But for ordinary people, fate after death may be the result not just of moral content in the spirit, but because of bad luck or unskillful navigation of the transition through death. If death takes place in an unsacred place, in a place full of polluting and dark forces, such things may stick to the person’s spirit and sour their rebirth, or even cause them to become a ghost for a time.

With my medical student friend’s explanation of ghosts and hospitals, his word “unsafe” and Jae’s word “safe” came into relief. The hospital is a powerful place, full of equipment and knowledge. But the power in the hospital is not moral power.<sup>19</sup> The hospital is a place of practical power. On a metaphysical level, it is amoral and dangerous, potentially infested with the polluting spirits of those who have suffered inauspicious deaths. The hospital is thus a bad place to die, full of the hovering potential

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<sup>18</sup> In Northern Thailand, the body is cremated at the end of the funeral (an odd number of days, usually 3, 5, 7 or 9 depending on the fall of auspicious dates). But the fire is usually not hot enough to destroy the bones, and this physical remnant is enough to keep the spirit in this world for another hundred days until the bones are destroyed, and a final transition ceremony is performed. The period between death and cremation, and then between cremation and the destruction of bones, form two distinct “intermediary periods” (Hertz 1907) between life and rebirth.

<sup>19</sup> An interesting exception to this is the fact that doctors and nurses themselves are seen as moral figures. In most Thai hospital ghost movies, doctors and nurses are moral figures who create safety and calm. It is only when the doctor or nurse leaves the room at night that ghosts and their amoral, unsettled powers emerge.

of becoming a ghost, missing the protections that preside in locations containing moral power.

This is not to say that all of the people I followed “believed” in ghosts. In fact, belief in ghosts seemed always contingent and negotiated, as it was for the nurse talking about the haunted bed, and as other scholars have noted about “traditional” or “superstitious” beliefs (Pigg 1996). But despite the hovering uncertainty of ghosts’ reality, nearly every person I interviewed about the desire to die at home mentioned ghosts. Janpeng even mentioned them affectionately, selecting the word spirit (*winyān*) instead of ghost (*phī*) to emphasize that she hoped her dead mother would be happy and have a good rebirth, but stay at home after death for a while to look in on her, moving a door occasionally, or dropping a cup from the cupboard to let her know that she was there, watching. But most referred to disembodied spirits as unhappy and unhealthily attached to things of this world, and they wanted to prevent their relatives from that fate. The way to prevent this was to get them out of the hospital to die at home.

Ghosts are one piece in a vision of the hospital as a powerful but problematic place – full of the amoral forms of modern power that can give life, but also full of potentially polluting and dangerous forces and void of the traditional sacred elements necessary for a good transition to the next life. The hospital is out in the bare and amoral world, off the grid of spiritual protection.

When Janpeng said that the hospital was safe, she meant that it was able to confer life and prevent death. She meant that the hospital was a safe place for *life*. But she was also torn, because as the death of her mother approached, she acutely felt how *unsafe* the hospital would be as a place to *die*. It was populated by dangerous and amoral elements

and empty of the sacred elements that could ensure a safe transition to the next life.

Janpeng was worried about her mother becoming a ghost, or at least about her rebirth being tainted by inauspiciousness. The way to solve this problem was to get her mother home.

This second ethical framework governing death in Northern Thailand begins to come into relief against the other frameworks available in Kiang's hospital room. The sign on Kiang's wall and Nurse Ampha's training both push Kiang to think of her death as more than a moment, as more than a set of decisions made by her family when she is already unconscious, with only hours to live. They push Kiang to think of dying as a long process, as the "end of life," something that needs to be known and faced over a long time. And the second framework is also in tension with the imperative to give life. The hospital is a powerful place to give flesh, blood and breath through medical knowledge and modern technology. Family members thus feel compelled to keep dying relatives at the hospital as long as possible, to pay back their debt as thoroughly as they can. But at some point, they need to get the dying individual home, so that the spirit can separate from the body in the appropriate place. The two frameworks thus exist in tension to one another. How is the transition between them navigated? Who decides when one has ended and another begins?

## **The Last Interval and the Journey Home**

Death takes place at the moment when the spirit separates from the body. The success of this separation depends on place. Spirits that leave their bodies when they are at home receive protection and merit from ceremonies. And at home, the mind does not cling to life because a dying person's possessions and loved-ones are all nearby. There is nothing to be missed. The hospital, on the other hand, is a barren and amoral place. Nothing is familiar, and it is full of polluting and dangerous elements. The hospital is a dangerous place to die.

The first patient I met at the hospital in Thailand was unconscious in the ICU. I held her hand for a bit, and spoke to her son, Chat, who was standing vigil by his mother's bedside during ICU visiting hours. Everything felt calm, and the son seemed to be handling her difficult condition with confidence. I had just met them, and couldn't ask much, so we just stood together. Then visiting hours were over and Chat had to go outside and wait with some of his siblings in the hall. I left them there with a few words of encouragement. They seemed shocked, but stable.

An hour later, I came back, and everything had changed. The son was frantic. His siblings were not there. "The doctor said that her condition is worsening and will not get any better, and there is no more treatment we can do..." he said. He pulled out his cell phone and looked at it in panic.

"We have to get her home right away. My brother went to find a pickup truck."

"What can I do to help?" I asked, and he shook his head. I didn't want to obstruct his urgent mission, but I wanted to help, and I didn't quite understand. So I asked, "why do you have to get her home?"

“Because if her spirit goes here, it will get lost,” he said. “She might not find her way.” It was clear from the terror in his face that this would be a very bad outcome.

We were interrupted in our exchange by Nong, a senior nurse in the ICU, who came out into the hall to tell Chat something with a calm urgency. “Your mother is getting worse quickly. I think you should go be by her side.”

We rushed in and stood around the old woman’s bed.

Nong, one of my favorite people in the hospital, had a depth to her. She began to talk slowly and continuously, narrating the events happening in the dying woman’s body. Her heart was beating slower and slower. Chat took some money out of his wallet and put it into his mother’s hand, and then leaned over and began to whisper in her ear, saying things she should have in her mind as her spirit separated from her body. Then her heart stopped and we all stood listening to the quiet buzz of the flatline on the heart monitor.

It was my first experience witnessing a death in Thailand, and I was stunned by everything that was happening so fast. We all walked out into the hall. Nong asked Chat if I could attend his mother’s funeral, and he looked very pleased to have something to do other than think about what had just happened. Helping me offered a way to make merit and do something kind instead of sitting in his grief. I took down the address and information, following Nong’s lead.

It was only later that I would come to realize what lay behind Chat’s panic and his claim that “his mother would get lost in the hospital.” In that moment, standing in the hall after her death, I thought that my fieldwork moment was over. It was only later that I

understood it had only begun, that I should have followed Chat and his recently deceased mother home, to watch how the problem of dying at the hospital could be fixed.

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The second phase of dying, what nurses and patients referred to as “the last interval of life,” is dominated by an imperative to optimize the passage of a person’s spirit into the best possible rebirth. This phase is strongly linked to place, to dying at home.

The two ethical phases of dying create a tension. The first phase, dominated by an imperative to give life, requires the life-giving power of the hospital. This phase must be extended as long as possible, to maximize paying back the debt of life. But at some point, there must be a transition. Someone must decide that life-giving is over, and the moment of death must be orchestrated to take place at home.

This transition has only begun in Kiang’s hospital room, as the theatre of life-giving begins to dissolve, as Kiang starts to advocate for going home. But the transition can be seen more vividly in the two faces of Chat: first, when I stood calmly with him by his mother’s bed and then one hour later standing in the hall, his face flush with panic, cell phone in hand. Preparing to make this call, he stood on a taut wire between two ethical frames, ready to push a button to mobilize a series of activities geared toward death rather than life.

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“We have to make it home,” said Jandi’s son, who sat across from me as I pumped air into his mother’s lungs to keep her spirit attached to her body.

Jandi was a rice farmer from a remote mountain village, five-and-a-half hours from Chiang Mai. She had been sick for a long time with a cough, but she had refused to go to the doctor because the ride to the city was too expensive, and her family had nowhere to stay if they came. Her daughters insisted that she go, but every time they would try to take her, she would escape off somewhere in the village. She was stubborn, and they grudgingly acceded to her wish not to go to the hospital. One day, after a fit of coughing blood, she collapsed while making food in the house, and they borrowed a truck from the village headman and drove Jandi to the hospital five hours away in Chiang Mai.

“She finally agreed to come?” I asked her daughter.

“No,” she replied, “she was unconscious. She would never have come if she were awake.”

The doctors were unsure what she had. Probably either tuberculosis or lung cancer, because she was coughing blood. Either way, her disease was advanced. Her chest X-rays showed lesions in many lobes and the snowy-white of fluid throughout. She didn't have long to live.

I visited the family first in the morning, and then again in the evening. When I arrived, the daughter met me at the door. “Would you help us? We need to take mother home.”

I said of course. I hadn't gone home with a patient like this before, although I vaguely knew by this point that we would be orchestrating her last breath to take place in the right environment.

“When are we leaving?” I asked.

“We're waiting for the ambulance to be prepared,” she said.

*Ambulance?* I thought, and then I realized that Jandi was on life support, a machine pumping her fluid- and blood-filled lungs. If we were going to get her home for her last breath, we would have to pump her lungs the entire way.

The head nurse of the surgical ward pulled me aside out of the conversation, and asked me in a whisper, “have you ever removed an endotracheal tube before?” I said no, suspecting where this was going. “Here’s how,” she said, and she pulled a plastic ET tube out of the cupboard and showed me how to deflate the balloon that held it in place. Apparently, as the most medical person around, I would be in charge of orchestrating the last breath.

Suddenly, everyone launched into action. Jandi’s daughters and two nurses took on the energy of EMT’s. The nurses withdrew Jandi from the mechanical respirator, and as we wheeled Jandi down the hall to the parking lot, they demonstrated to me how to pump air into her lungs with the balloon pump.

The “ambulance” that we had been waiting for was a pickup truck owned by one of the hospital gate guards. He ran a small business on the side of his guard duties, taking people home to die. His truck was cheaper than a real ambulance, and it was equipped with two tall green oxygen tanks, and a motorcycle tire pump that he had reconfigured to pump embalming fluid in case a patient died on the way home. We had been waiting for the guard to find a friend to accompany us on the journey, since it would be so far. He needed support for the long ride back in the middle of the night.



Figure 2. The guard's pickup ambulance with oxygen tanks and mattress



Figure 3. The guard's vein cut-down kit and improvised motorcycle tire pump embalming apparatus with attached large-bore needle.

I took over pumping the bag ventilator, but the family began to fuss about me getting blood on my clothes, and insisted that the guard's assistant take over or that we share the duty. I helped lift Jandi into the truck, and then sat in back as we left for the mountains. Six relatives followed in the truck they had borrowed from the village headman.

Soon we were in mountain jungle. We whipped around corners, pushing the car as fast as possible. It smelled vaguely of pine smoke and mint outside.

"We have to make it home," said Jandi's son, who sat across from me at one point as I took my turn pumping air into his mother's lungs. "If she dies on the way, we have to change places so I can talk her spirit through getting home."

I nodded.

"You take her pulse," he said. "If she dies, please tell me. We have to go to a temple instead of home."

"Why?" I shouted above the hum and screech of the car.

"There are spirits (*phī*) all along the way!" he said. "They might cause her harm, or bring something bad along. At the temple, the monks will help. Bad spirits can't enter."

I took Jandi's pulse; it was still there, though hard to tell over the shaking of the car. I looked at her ET tube, which was full of blood. I couldn't imagine I was providing her any oxygen, just pumping air into blood-filled lungs. But the tube was connected to the oxygen tank in the guard's truck, so she might have been getting enough oxygen.

By this point, we were going at extraordinary speeds. I struggled to keep pumping and keep my balance, so the guard's assistant took over again. I crawled to the back of the truck to retch and then returned to my job of pulse watching.

The son shouted over the hum, "The guard said that he can make it there in three hours. It normally takes five-and-a-half. I think we'll make it."

I nodded my support, and started breathing exercises for the motion sickness. It was the hot season, the season when mountain dwellers burn the forest to make a fertile bed for mushroom harvesting in the rainy season. As the sun set, I could see the forest glowing with fire all around us. We barreled through the burning forest, skidding around curves, holding Jandi's spirit to her body only with an endotracheal tube and a hand pump.

When we arrived in the village, the road changed from paved to dirt, and the guard slowed his driving. Jandi's son looked up and said, "we're close. She should know we're here. Grandmother, smell the air!"

As if on cue, Jandi woke up for the first time in many days. She looked at me and at her son, and she looked surprised but not afraid. The guard's assistant pumped a breath into her blood-filled lungs, and she coughed up a huge splash of blood and then closed her eyes again.

"See!" said her son, "I knew she would make it! She has so much heart power!"

We pulled into their house, greeted by three dozen villagers. We lifted grandmother in her mattress and carried her up to the second floor of the teak house, continuing to pump her lungs. We set her down. The guard followed us up, and as soon as Jandi was set down, he said, "now it's time to take out the tube."

“No!” interrupted Jandi’s daughter, “can we wait until the second car arrives? If they are not here, she will miss them.” How precarious the crafting of the moment of death! Such an emergency, even getting relatives there.

Ten minutes later, the second truck arrived, and the house was full to the brim with people. All eyes turned to me for a moment, and it was clear that it was time to withdraw the endotracheal tube. I hesitated and the guard stepped forward, clearly eager to provide this service, which was part of the fee he was charging the family. I was relieved, still unsure of the ethics and legality of withdrawing the tube myself. He used a syringe to drain the balloon of air, and then slowly pulled out the tube.

Jandi woke up. They propped her up on pillows, and she looked around at everyone gathered together to see her off. Thirty people stood around and shouted out to her: “We love you grandmother!” or “You’re home!” Jandi’s daughter brought a bowl of boiled rice porridge and held up a spoonful to her mother’s mouth. She took a bite of it, tasted it, looked at her daughter and smiled. Everyone reached out and held her legs or her arms. All of her things were gathered around her, above the head of her bed. She locked eyes with people in the crowd, each in turn, not with everyone, but with a few people. And then she coughed, a huge splash of blood, and coughed again. And then she closed her eyes and died.

We sat in silence for a while, and then people began to file out. One of the guests invited me to go, and I realized that whatever would happen next was private, and I left the family together.

“That was good,” said one of the siblings when I got outside, “they took her to the hospital to try to save her life, and then they got her home.”

“That’s important, isn’t it?” I asked.

“Yes. She had her things around her. Everyone was there. She wasn’t worried about anything. It was very good.”

We all stood in silence for a while. Someone told me I should go sleep and leave the family to take care of the corpse. The guard excused himself, and I walked with him back to his truck, which he would drive all night to get home.

“How do you feel that went?” I asked him.

“It was good,” he answered. “The family took out a loan and sold a buffalo to pay for all of this. I think it was worth it.”

Three days earlier, Jandi was in her house, standing just an arm’s length from where she had just died. But those three days – going to the hospital to give her blood, breath and flesh, and then rushing home for her last breath – were well worth a buffalo and a loan. Everything had gone according to plan.

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Mr. Peng died at the hospital. He was on a mechanical ventilator, and there was some hope of being able to take him off of the breathing tube so he could breathe on his own. But he got an infection in his blood, and his blood pressure dropped, his heart stopped and they could not resuscitate him.

Mr. Peng’s daughter and niece, Bua and Phai, were still engaged in the process of giving their father life because they didn’t feel like he had yet entered into the last interval of life. They were the ones, two days before, who sat in the hall and told me about their debt of flesh, blood and breath to their father. Neither of them was there when Mr. Peng died because it was early morning, long before visiting hours. But they

both came rushing when the nurses called to tell them. When they got to his bedside, Phai began to whisper in his ear. “Grandfather, we’re here,” she said. “Stay with us, you need to stay nearby.”

When they put Mr. Peng in a truck to take him home, Phai continued to talk to him, explaining where they were going. “Grandfather, we’re passing the Tesco Lotus on the big road, do you remember? Do you see the Tesco Lotus? Stay with us, we love you, we are right here. Now we’re turning right at the motorcycle repair shop, do you remember?”

Phai needed her grandfather to make it home. If he lost his way, if he forgot to follow his body because he was confused or scared, then his spirit might get trapped in the hospital, or in an unfamiliar place along the road. The ceremonies to transfer merit to his spirit would not work as well. And so she coached him through following his body home.

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The families of both Peng and Jandi were caught in a tense transition between ethical frameworks, between giving life and dying at home. And in this transition, they built elaborate strategies to allow them to optimize both ethical frameworks. Jandi’s “last interval of life” was long enough that her family was able to rush her home, the threshold to her room like the finish line in a race with death. Peng’s last interval of life was too short, and so he died in the hospital. But Phai was there to whisper her elaborate monologue in his ear, to keep his spirit close to the familiar protection of his body and family, to prevent him from getting lost among the dangerous and polluting forces occupying the space of the hospital and between hospital and home.

These two ethical frameworks, governed first by life and then by place, form a stable, negotiated truce in the experience of dying in Northern Thailand. It is into this already complicated ethical world that new frameworks are arriving, frameworks alien to this stable, negotiated combination. The sign on Kiang's wall and Ampha's idea of Kiang as a seeker of wisdom both want Kiang to make decisions about her death, to engage and experience it with active knowledge that would require casting off both her family's crafted ignorance and the need to push the last interval of life to the very shortest possible moment. The new frameworks want Kiang to manage her experience, make her own decisions about receiving life, and craft her own transition home. They want to pull and stretch the moment of death until it can incorporate knowledge and experience. And so the frameworks that have come together in Kiang's ethical world clash and slip against one another.

## **On Places and their Ethical Worlds**

I met Euai when she was already in the last interval of life, on the day of her death. She was in the ICU, crashing fast from renal failure and a blood infection. Her children were gathered together outside the ICU, and they decided that it was time to take her home. Their decision was complicated, and I would later learn that it was partly because Euai was suffering so much in the ICU without any pain medications, and they couldn't stand to see her pain. But when I first met them, it seemed simply that they had moved on from giving her life to arranging the optimal place for her death.

Euai was on a mechanical ventilator, a breathing tube inserted into her lungs and attached to a machine that pumped the lungs artificially with positive pressure. I assumed we would be bag ventilating their mother home, just as I had witnessed several times before.

Many Thai physicians refuse to withdraw ventilators from patients because it feels like killing. Unlike physicians in the West, they describe withdrawing ventilators as “active euthanasia” or “mercy killing” (both in English) because even though life-support machines artificially pump the lungs, removing them results almost immediately in death. Some of this is supported by a Buddhist explanation of the mechanics of human life, which is contained in the contact between consciousness and the four elements of the body, and particularly and ultimately in the breath, which is the final element to separate from consciousness. Pulling out a ventilator thus feels, to some, like pulling out a patient's consciousness. But the reluctance to withdraw ventilators is also a legal fear, a fear that the family will accuse them of killing. Some physicians do not allow any

ventilator withdrawals. Some allow the family to withdraw the ventilator, so that they will incur the negative merit and the legal responsibility.<sup>20</sup>

Euai's doctor was Dr. Prani, who told me that she did not withdraw ventilators from patients. I was thus surprised when the nurses began to prepare Euai for transport home, and nurse Nupa told me that they were going to withdraw her ventilator.

"Why?" I asked quickly before they closed the room to me.

Nupa answered in a rush, "because she can breathe a bit on her own." I looked confused, and she added, "we think she can make it home before she dies." Then she excused herself to go prep the patient.

The family asked if I would help them home. We loaded Euai, breathing shallowly and arrhythmically, onto a mattress in the back of a pickup and set off. It was rush hour in Chiang Mai, and we sped dangerously through traffic, passing cars on the wrong side, driving up on medians to get around the congestion. When the traffic cleared, the driver pushed the car into a frenzy. Euai could breathe on her own for a time, but if we dallied in traffic she might die on the way. We made it home, lifted her out of the truck and took her into her room, where her grandchildren had gathered all of her possessions. When she arrived, she calmed down and her breathing became rhythmic and she opened her eyes. She smiled and looked around, clearly glad to be home.

"See," her daughter said to me, "she just needed to get out of the hospital. It is a bad place." She lived for another ten hours before dying.

The next day I went to the hospital, and nurse Nupa pulled me aside, "did that patient make it home?"

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<sup>20</sup> For a more in-depth discussion of the ventilator issue, see my masters project (Stonington and Ratanakul 2006).

I told her that we made it and that she lived another ten hours.

Nurse Nupa looked relieved. “Oh, good,” she said. “We thought she could make it home.”

“What would have happened if she didn’t make it?” I asked and then suddenly regretted asking such a direct question on such a sensitive issue. It might have sounded like I was questioning her decision.

“It would have been a bad outcome,” she said generously. “We love our patients, and we want them to do well. That’s why we don’t withdraw ventilators in the hospital. We want them to make it home.”

I thought suddenly of the nursing team preparing me to withdraw Jandi’s ventilator tube in her mountain village. At the time, there was no question about the ethics of me withdrawing it, or about its effects on my karma. The only thing at stake was whether we would make it home before she died. The ethical framework behind the decision to withdraw an endotracheal tube was entirely about place. Nurse Nupa and her team eagerly asked me about whether the patient had made it home, because the ethics of their decision depended on the place of the patient’s death. If she had died on the way, they should have sent her with a bag ventilator and had me withdraw it at home. It wasn’t the act of withdrawing the tube that was the ethical focus, but the place of death that resulted.

The last breath is the penultimate moment of the second phase of dying in Northern Thailand, of “last interval of life.” And the ethical focus of this moment is place, the location of death within a metaphysical landscape. And because of this metaphysics, the act of withdrawing a ventilator has a different ethical overtone

depending on where it occurs. Though it would be too black-and-white, one could almost say that withdrawing a ventilator in the hospital is wrong but withdrawing it at home is not.

This is not dissimilar to the first ethical phase of dying in Thailand, the phase of giving life. The single act of telling a patient her diagnosis has a different ethical overtone depending on the level of mind of the patient. The sign on Kiang's wall that declares her "right to know her diagnosis" knows nothing about her level of mind. It addresses an act, the act of disclosing information. The particulars of the recipient of the information are irrelevant. The sign proposes that Kiang is a universal subject, a citizen of Thailand with a right that cannot be removed from her, regardless of her "level of mind."

The dependence on place in the second ethical phase of dying raises a similar, but less sharply delineated issue. Physicians and nurses are afraid to withdraw ventilators for two reasons, legal and spiritual. Both of these reasons vary with place. Providers fear legal action by the family for "killing their relative," but a lawsuit would be much less likely if the withdrawal occurred at the patient's home, where the family's dominance over decision-making is clearer. Similarly, providers fear the metaphysical consequences of withdrawing ventilators, but the karmic fall-out of this act is much smaller at home, where the harm done to the spirit is less dramatic. The spirit is in the right place to die. It is a better outcome, spiritually, and so it is less karmically dangerous as an act.

The rights discourse that is arriving in the hospital brings with it a principle-based way of approaching ethics that focuses only on actions. Telling a patient her diagnosis is right; withdrawing a ventilator is wrong. But in the ethical frameworks already dominant

in the hospital in Northern Thailand, these act-based principles are either tossed aside, or negotiated into a complicated patchwork. Patients are told their diagnosis based on their level of mind. Ventilators are withdrawn at home more often than in the hospital. Acts are attached to cases, to individuals, to places. And so the ethical frameworks governing those acts are based on things specific to situation – to levels of mind and to place.

### **Providers as Technicians of the Sacred:<sup>21</sup> Manipulating Biology for Place**

Mr. Tawo's son Loek – who had so much *phūkphan*, such ties of affectionate duty with his father – was slow to decide that his father had entered the last interval of life and thus needed to go home. Loek's wife Nai felt that Loek's *phūkphan* itself was causing him to hold on, and that the old man should be allowed to go peacefully, that he should be taken home to die.

Tawo knew that if his condition worsened without killing him, his entry into the last interval of life would be undeniable, and so they would take him home, and he would be more likely to die at home. If not, his vigilance might eventually fail, and he might fall asleep in the hospital and not wake up. So he tried to strangle himself with the oxygen hose. But he failed, and they did not decide that he was in the last interval of life.

Tawo's heart stopped in the middle of the night, and the nursing staff resuscitated him twice, putting him on a mechanical ventilator and blood-pressure medications. The next day, they kept the breathing tube in and continued his blood-pressure medications so that he could make it home to take his last breath.

Why did they resuscitate Tawo? Partly, it was an incomplete transition to the last interval of life, because Loek had only just begun to realize that giving life needed to end. They were simply waiting until the next day to withdraw life support and let him die. But the purpose of the CPR in the middle of the night was to keep Tawo alive so that he could make it home. The care team manipulated his medical care largely to orchestrate the correct location of death.

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<sup>21</sup> This phrase comes originally from Jerome Rothenberg (Rothenberg 1968), but my use of the phrase is borrowed from Felicity Aulino (Aulino 2008b), who used the term to describe the spiritual role of doctors in Thailand. This line of inquiry also owes a great debt to Vincanne Adams (Adams 2001).

So who decides when a patient has entered the last interval of life and needs to go home? The obvious answer to this question is contained in Chat's explanation to me about why he was suddenly in a panic to get his mother home after I had seen him calm just an hour before: "The doctor said that her condition is worsening and will not get any better, and there is no more treatment we can do. We have to get her home right away. My brother went to find a pickup truck."

The transition to the last interval of life is a switch between ethical frames, and it is a metaphysical transition. It is a switch from a process of making merit by giving life, to a process of making merit by giving the right kind of death. The brokers who decide when this transition is taking place are healthcare providers – doctors and nurses.

Tawo knew, when he tried to worsen his condition in the middle of the night, that the ultimate decision about his place in the last interval of life was in the doctor's hands, and that he needed to be sicker, he needed to be closer to the threshold of death for them to take him home. Healthcare providers are the technicians who determine when the last interval of life has begun.

The job of the healthcare provider, in turn, is to make sure that the transition happens smoothly and that patients end up with their last breaths at home. And so they manipulate health care to make this more certain, by providing blood pressure medications and bag-ventilators to get home, or by doing CPR to keep someone's consciousness attached to their body, to ensure a death at home.

In her book *And a Time to Die*, Sharon Kaufman shows how death in the modern hospital is structured by an imperative to control the timing of death. The passive "waiting for death" that used to dominate dying in the West has been replaced by a

bureaucracy that controls and makes decisions about every phase of dying. The bureaucracy itself runs on an intractable concept of time – controlling it, shaping it, maximizing it. And so dying itself becomes a process that is always timed and controlled. And this time-dependence interfaces with ideas of the “good death,” held both by providers and patients, to produce an ethical framework that revolves around controlling the timing of death (Kaufman 2005).

The ethical framework operating in the “last interval of life” in Northern Thailand is also about time, but time is subordinate to place. A healthcare provider must predict and manipulate the timing of death so that the last breath is ensured to take place at home, not at the hospital. If death is coming too quickly, it must be slowed with equipment and medications until the patient can make it home. How sick is the patient? How far is home? These factors are synthesized into a single decision that is both about place and time. And then biology is manipulated, ventilators are withdrawn, drugs are administered, a patient’s heart is restarted with CPR, all to optimize the arrival at home with breaths left to take.

## **Dying in Northern Thailand**

Kiang's hospital room is an ethical world, inhabited by a set of ethical frameworks, some overlapping, some conflicting, some harmonizing. Two of these frameworks, and the tension between them, dominate the scene. The first is an imperative to pay back a debt of flesh, blood and breath. The way to achieve this payment is to prevent a patient from thinking too much by giving heart power. And depending on the level of the patient's mind, this heart power sets up an ambiguous relationship to truth-telling and knowledge. Patient, family and health care providers engage in a theatre, where heart power is performed and everything else dances around it.

In the last hours of life, when death is imminent, a second ethical framework takes over, governed by an imperative to escape the polluting, dangerous forces of the hospital and bring a dying individual home for optimal separation of body and spirit. Health care providers determine when this transition takes place and they manipulate biology to ensure its location.

These two ethical frameworks hang in tension to one another. The amoral power of the hospital is necessary for giving life, but becomes a spiritual hazard at the moment of death. In the transition between frameworks, dying patients and their families navigate complex, emergency strategies to keep both frameworks satisfied.

In Kiang's hospital room, these two ethical frameworks form a status quo. They are not pre-modern, because they are both wrapped into the modern-ness of hospital death. But they form the current understanding of how dying works in the Northern Thai hospital. They, in turn, exist in tension with new ethical frameworks arriving in Kiang's room: with Ampha's desire for Kiang to use the experience of her dying process to

improve her mind; with the sign on Kiang's wall, which wants her to know explicitly that she is dying and make her own decisions about her dying process.

Neither of the two dominant ethical frameworks in her room requires a knowing subject. In the phase of paying down the debt of life, ignorance is usually valuable because of its relationship to heart power. Kiang must "keep up her heart power," and Jae must give her more of it, and ignorance is the primary mechanism to achieve this. Likewise, the length of the "last interval of life" is determined by the minimum time required to take the last breath at home, and so it is not about conscious experience. Death is only a moment, not an experience, and lack of conscious experience is often used as evidence of being in the last interval of life.

The new ethical frameworks arriving in Kiang's hospital room carry with them a new object, the end of life. This object does not exist in the two frameworks currently dominating the hospital, or in the tension between them. The end of life is a shift in focus from the moment of death to a longer interval, during which time a dying patient can face the experience of dying and exercise spiritual and legal will to control it. This new period of time, the end of life, has begun to push on the way of understanding the process of dying in Kiang's room. Its effects are still sometimes subtle, as with Ampha's gentle worry for Kiang's soul from the hall. Sometimes its effects are louder, as with Dr. Danai's accidental revelation of Nanban's cancer and his self-defense with with Nanban's "right to know."

In the following sections, I explore the history and essence of the new ethical frameworks arriving in Kiang's hospital room. And then, equipped with an understanding of the frameworks, I explore what happens when they collide.

## **Section II:**

### **Ethical Assemblages: Crafting the End of Life**

Jae and I sit on her mother Kiang's hospital room floor, crying and whispering in English about the cancer in her mother's body. We speak English because if Kiang overhears us, she might guess her disease and prognosis. Jae is engaged in giving her mother life, in paying down the debt incurred by birth. She is paying this debt by giving her mother heart power, by protecting her from the truth of death looming over them. Kiang lies dying of cancer, subtly knowing and not knowing about her own death.

Above our heads, the only sign in the room reads: "Things you have a right and responsibility to know during your stay in this hospital: your disease, treatment you are receiving for your disease, and self care appropriate for your disease." The sign, as a stand-in for a set of policies, has a vision of Kiang as a certain kind of patient, a rights-bearing and rights-wielding citizen, a knowing subject rather than a passive object of health care.

Outside in the hall, Nurse Ampha worries quietly about Kiang's mind. She says: "Mother Kiang will have no chance to prepare her mind for the final moment. How can she know she needs to meditate and chant if she doesn't know what is happening?" Ampha has a vision for Kiang – she wants her to be a certain ideal kind of patient, a woman who can face the truth of her death and use this knowledge to prepare and improve her mind.

Ampha also looks exhausted from a long work shift in the understaffed hospital, but her eyes light and her posture rights when she talks about Jae's mother and the coming 'final moment.' Her eyes fill up and a smile comes to her face, and I can see that thinking about it fills her with heart power. She has trained, in a distant government bureaucracy in the country's capital, to talk to patients about the spiritual contents of

dying. And more than that, she *wants* to talk about them. She would rather spend her day preparing Kiang's mind than writing in a chart and checking vital signs. She has a vision for herself – she wants to be a certain kind of healer, one whose job is primarily to help patients through the dark but inspiring tunnels of fear and death.

As Kiang lies softly dying in her high-tech hospital bed, her room is inhabited by each of these visions: the figure of the rights-bearing subject, of the patient seeking wisdom, and of the healer finding meaning in practice. These ethical figures have traveled from elsewhere to land in Kiang's room. Some of them began in global discourses, others in national politics. They have traveled here, transformed and mutated by their journey, and landed in Kiang's room, where they clash with the other ethical frameworks inhabiting Kiang's room, with Jae's imperative to pay down her debt of life and Kiang's imperative to die at home. Kiang's hospital room is an ethical world where frameworks collide and push on one another. Where do they come from? How did concepts about patient rights come to dominate Kiang's wall? How did Ampha learn to seek meaning in medicine by discussing death with Kiang? And who decided that Kiang should face her own death and find wisdom through the experience?

Kiang's room is a site of social change. Previous ways of thinking and acting toward death have been destabilized. Certainty about right action has been evacuated from Kiang's room, leaving an opening for new ethical frameworks to rush in. What has destabilized thought and action around death? Where did the opening in Kiang's room come from?

This section is about a series of historical forces and events that have destabilized previous ways of thinking and acting in Thailand, and about the agendas and ideas that

have begun to fill the gap left behind. It is about how death and dying found their way into a complex historical landscape, and about the emergence of a new kind of death, the “end of life,” a death based on knowledge and experience and empowerment.

## **Chapter Three:**

### **Social Change and the Uses of Death**

In 1991, Army Commander Suchinda Kraprayoon led a military coup to overthrow a democratically elected government. In response, demonstrators took to the streets to protest his rule. The military attacked the protesters, arresting and torturing thousands, killing hundreds. Images of this brutal military response hit the domestic and international media, forcing Suchinda to resign and creating an unprecedented wave of political will that galvanized reform movements throughout Thai society. This series of events – resistance to military rule and then the military’s dramatic failure in response – destabilized the traditional political structures of Thailand and created an opening for an assemblage of new ideas to come rushing in.

May 1992 was not, however, an isolated political cataclysm. Instead, it was a sudden shift, a punctuated equilibrium, in a long history of social change in Thailand. What are the traditional political powers in Thailand? What has made them start to destabilize, creating an opening for new forms of thought and action to emerge?

A summary of traditional Thai power can be found in the simple statement made by Suchinda as he stood before the Thai public to justify his military coup. He wanted “to sustain the security of the three institutions – Nation, Religion, and Monarchy” (Murray 1996). The roots of these three institutions extend back hundreds of years into Thai history. In contemporary Thailand, these institutions have begun to destabilize. But

to understand their instability, one must first understand their history, their roots in the traditional social landscape of Thailand.<sup>22</sup>

### **Roots: Monarchy and Religion**

In the seventeenth and eighteenth centuries, political power in Siam was feudal. Nobles ruled city-state centers (known as *meuang*), with spheres of influence that decreased with distance over surrounding areas, like layers of an onion. Within each city-state, rule consisted of hierarchal bonds of subordination, in which inferiors paid produce to superiors, up a chain of power from peasant to noble. Meanwhile, a second source of power grew slowly within the religious clergy, the *sangkha*, which by the eighteenth century had fused pre-modern Tai animism,<sup>23</sup> Hinduism from India and Buddhism from Sri Lanka into a coherent whole that exerted influence over all aspects of daily life and exerted increasing influence in politics. Lay people patronized the *sangkha*, and a large portion of men spent time rotating through it as monks.

By the mid-eighteenth century, these two sites of power, royal and religious, had fused into one. The ruler of the *meuang* was a *thammarāchā*, a fusion of royalty (*rāchā*) and of the body of the Buddha's teachings (*thamma*) into a single figure, master of both political and religious power. The concept arose from an assumption that royal birth must confer a virtuous power, and it eventually expanded to the point that prominent

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<sup>22</sup> The following history of Thailand comes from (Baker and Pasuk 2005), (Wyatt 2003) and (Wright 1991). Information from other sources and significant points of disagreement between the three core sources are cited directly in the text.

<sup>23</sup> The word Tai refers to the larger language family and set of cultures including the people who occupied the Chao Phraya River basin prior to the arrival of Buddhism, Hinduism and the Sanskrit and Pali languages in Southeast Asia (Wyatt 2003).

monks were able to critique and influence royal acts that deviated from religious morality (Tambiah 1976).

In 1767, the central kingdom of *Ayuthayā* was sacked by the Burmese and its royal line was destroyed. Without a lineage to justify leadership in Siam, a power struggle ensued, dominated by a set of wealthy families that had become integrated into religious power. To create a framework to justify leadership, these families evoked and expanded the idea of *thammarāchā*. No longer was royal power conferred by blood-line, it was conferred by religious righteousness. Using mostly Brahmanic ritual, they instated a new King by ritualistically infusing him with Kingship. His lineage was attributed not to worldly birth, but to a succession of incarnations. The King was a Bodhisattva (*phōtisat*), a nearly enlightened being who had chosen to be reborn as King to lead the people to salvation, and his blood-line continued with worldly births of holy beings reincarnated to carry on this task. Power in Siam was consolidated into a coherent unification: State was King was Religion.

### **Roots: Nation**

In the nineteenth century, European powers began to expand their influence into Siam. After humbling China in the Opium War of 1842, John Bowring signed a trade treaty with Siam, the first event of a looming European domination. The agricultural economy that supported feudalism diversified and became more “bourgeois” (Nithi et al. 2005). The settled simplicity of King as religious head of a feudal state was suddenly in question, and reform seemed necessary. Through a combination of cunning, Occidentalism and haphazard understandings about the culture of European colonialism,

King Chulalongkorn (1868-1910) invented a way out: to transform Siam into a nation-state, and to rewrite Siamese history as the history of a nation. This elaborate illusion could be presented to European powers as an argument against colonialism. Central components of European understandings of States – borders and historical claims to territory – were not traditionally part of the Siamese *meuang*, which consisted of spheres of influence and cared not at all about borders or territories. Siam needed to rewrite this past, to create an illusion of nation-hood, to invent borders and craft itself a “geo-body” (Thongchai 1994).

The people falling within this newly crafted container needed to become citizens. Chulalongkorn outlawed the old feudal systems of slavery, indenture and bondage, which were forms of relationship to hierarchical superiors rather than to the State. He replaced them with conscription into a national army. He built the military to unprecedented strength. He began to reeducate inhabitants of his new Siam, which had always been a place of heterogeneous diversity, to think of themselves as a single race with one religion (Keyes 1987b). This helped match and evade the French colonial argument that nations must consist of one unified people. Chulalongkorn created a social education program to make Thais appear civilized (*siwilai*) to Europe, and sent the children of elite bureaucrats to study abroad. By the end of Chulalongkorn’s reign, he had constructed a national identity (Reynolds 2002). The old unifying concept of King-Religion as the top of a feudal state had been replaced by King-Religion-Nation, along with its newly “imagined community” (Anderson 2006) of Thai citizen-subjects. Royal power had been consolidated into an extreme absolutism, a monolith of state and religious power.

### **Revolution: King-Nation-Religion Split into Three Institutions**

In the early 20<sup>th</sup> century, the seeds of social change planted by King Chulalongkorn began to take on a life of their own. Elites returning from education in Europe used Chulalongkorn's own argument about emulating European nation-states to introduce republican ideals and begin to question the monarchy. Domestically, growing trade had produced a merchant middle class that began to think of itself as independent of royal power. Coincident with these ideological shifts, Chulalongkorn's son, Vajiravudh, began to mismanage the country. Absorbed in artistic pursuits, he bankrupted the royal treasury, largely to support personal aesthetic gratification. The nationalism first created by Chulalongkorn fueled a turn against the monarchy, which new thinkers accused of simply emulating European culture rather than developing a truly Thai nation, representative of the people.

In 1932, based on these ideals, a group of seven foreign-educated intellectuals staged a bloodless revolution and instituted a constitutional monarchy. By 1935, the King was forced to abdicate the throne, and though the monarchy was retained, it passed into the hands of the ten-year-old Ananda Mahidol, still at school in Europe. The monarchy retained its land and a moderating role in the constitutional government, but it was removed from rule over the military and civil bureaucracies. The religious clergy (*sangkha*) was made into an independent bureaucracy, and continued its influence through moral authority about the uses of power (Ishii 1986). The monolithic locus of power King-Nation-Religion fractured into three separate institutions, with most of the real power concentrated in the newly formed institution of the 'nation.'

## **Negotiating Control of the Nation**

A conflict-ridden process began to determine the form of the Thai ‘nation.’ A dramatic shift had occurred in the forms of political power in Thailand, creating an opening into which an assemblage of new political forms rushed. A conservative vision persisted, based on Chulalongkorn’s old ideals of unity (*sāmakī*) requiring a strong centralization of power, now envisioned as located in the military and in a small oligarchy of ruling elites. Opposed to this was a republican vision of decentralized and democratic power based on a broad, educated merchant middle class.

This uncertain space – the negotiation of ‘nation-hood’ as a new form of power – was not temporary, but persistent. It was, and remains, a continual engine of unsettled strife in Thailand. Gamontip Jaemgrajang (2002) summarizes modern Thai politics, beginning in 1932 with the fall of the absolute monarchy, as a continual cycle between the two poles of military and democratic nation-hood:

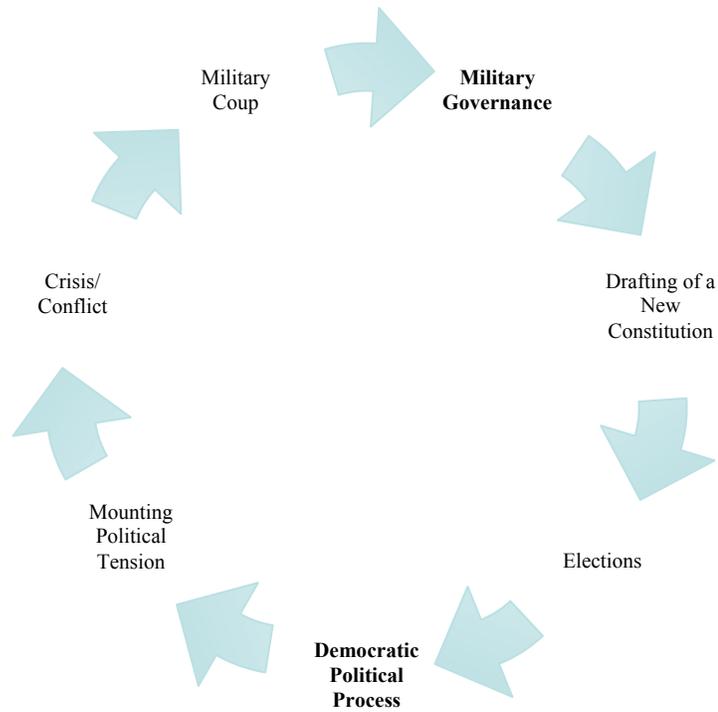


Figure 4. Gamontip's model of Thai political history as an oscillation between two ideologies attempting to define the Thai nation (2002).

Between 1932 until 2008, Thailand experienced twelve successful and seven attempted military coups, and had seventeen constitutions (Murray 1996), all roughly following Gamontip's model of political ideology.

Although the apparent form of the Thai government oscillated between military dictatorship and parliamentary democracy through each of these coup cycles, the reality behind this veneer varied little. Democratically elected leaders were almost always affiliated with the military and power remained in the hands of a small number of ruling elites. In such times, the outward political discourse contained rhetoric of decentralization, but little motion occurred toward democracy, and the Thai nation remained the absolutist military state established during monarchical rule (Murray 1996).

Out of this background equilibrium, however, two moments in Thailand's cyclic history stand out as cataclysmic transformations that destabilized the foundations of traditional political forms in Thailand.

In the 1940s and 1950s, Thailand was a strong, unopposed dictatorial state, bolstered by World War II and then the Cold War. The United States used Thailand as its primary stronghold in a war against communism, and saw military dictatorship as the optimal and safest government to craft in Thailand. At the same time, however, Thais were exposed to the contradictions inherent in American politics – using one hand to foster despotism and another to claim the ideals of democracy and freedom. In this era, a new generation of Thais came into adulthood, many of whom had studied in the United States and learned about a democracy implemented by active citizens rather than by gifts from government. Criticism grew of the role of the United States in Thai politics, especially with the Vietnam War in the late 1960s. A generation of students gathered voice, stirred into activism by communism, socialism and republicanism, galvanized by American students' protests of the contradictions apparent in their own government's agenda. Members of the religious *sangkhā* began to speak out against military rule as violating Buddhist morality. At the heart of this movement was the powerful figure of Buddhadasa Bikkhu, who broke with the conservative *sangkhā* to advocate for an engaged spirituality based on socialist ideals. Many of the student leaders of the growing activist movements were disciples of Buddhadasa's and used his Buddhism to back their campaigns.

In 1968 and 1969, the Thai government was putatively democratic, but as always, it was dominated by military interests, with a military dictator in the position of Prime

Minister. But the generation of reform-minded Thais began pushing democratic ideologies into national politics. Members of parliament began more openly criticizing military rule. In 1971, Field Marshall Thanom Kittikachorn, then Prime Minister and military dictator, staged a military coup against his own government and dissolved parliament and the constitution. In response, in 1973, 500,000 people took to the streets of Bangkok to protest this explicit seizure of government by a constitution-less military regime.

The military crackdown on the protests turned violent and soldiers opened fire into the crowds, killing hundreds and wounding thousands. The public was outraged by this violence, and tensions became extreme. Claiming that the violence represented an unacceptable division of Thais against Thais, the King intervened directly in politics for the first time since the 1932 revolution and “asked” the military dictator to step down and go into exile. The King then appointed a new prime minister and new government, which used the intense backlash against the military massacre to create the first truly open government in Thai history.

The 1973 massacre created a sudden destabilization of the traditional military structure of the Thai state, opening a space for new forms of thought to emerge. A flood of public debate over democratic issues ensued. The mighty hand of Thai conservative power had been momentarily lifted. There was an explosion of thought, publication, dialogue and conflict. Farmers, long oppressed under the feudal labor system, organized to advocate for farming cooperatives and price protections (Missingham 2003). Laborers organized to advocate for unions (Ockey 2004). Academics began to publish and distribute widely, vastly expanding the public sphere aware of a democratic movement in

Thailand. Thammasat University in Bangkok became a center of political foment and creativity. This intellectual activity – whether radical or progressive, communist, socialist or democratic – drew often on the Buddhist socialism pioneered by Buddhadasa (Jackson 2003).

The openness did not last long. As in all social change, previous social forms reassert themselves when their dominance comes into question. Strong-state activists began a propaganda campaign equating student activism and reform politics with violent communist revolution. In 1976, former dictator Thanom returned from exile amidst rumors that he would “protect” Thailand from dangerous communist rebels. The student gatherings at Thammasat University grew, and debate intensified. The military, with little pretense, surrounded Thammasat University and issued a general call to kill students of any kind. They were backed by conservative members of the Thai clergy who, threatened by the Buddhist reform inherent in activist politics, issued a statement that it was not a sin to kill communists. Soldiers, given a free hand, fired rockets, machine guns and anti-tank missiles into the University, and raped, tortured and killed students who tried to flee. The leader of the anti-communist backlash announced a military takeover and a total indefinite suspension of democracy. Activists fled to the rural provinces to escape arrest, murder and torture.

Despite the resounding military victory in this most intense of Thailand’s coup cycles, a movement had been born. The unapologetic brutality of the two military crackdowns of 1973 and 1976 galvanized people into pro-democracy ideologies. The activists had also undergone a dramatic growing-up process. The fantasy of a simple

student-led conceptual revolution was dead. Activists now knew that those with power would resort to massacre to keep it.

Eventually, subsequent governments backed off from the initial unmitigated despotism and granted amnesty to activists, who returned to normal public life. Since many of them had been students, they returned to scholarly studies and spread slowly out into the bureaucracies of Thai government, clergy and civil society, often with a conscious mind to infiltrating power structures from the inside, slowly advocating for political change from within. Thai bureaucracy, formerly synonymous with elite power, became a site of quiet political disagreement. Simultaneously, activists knew that they could not use the traditions of Thai society to argue for social change, because those traditions had themselves been wrought from hierarchy and centralized power. They began to reach instead for global social ideas to fuel their arguments, particularly the popular discourse on human rights coming from Europe. These activists were partly protected from total suppression by the traumatic national and global memory of 1976, and they were now bolstered by a globalizing conceptual landscape. Social critique grew, this time from within the ranks of Thai institutions. Activists in the religious clergy and in professional fields such as medicine, law and business conducted their careers with half a mind to infusing new political ideology into every policy and every case. The traditional forms of thought and action within Thai political, religious and civil institutions began to destabilize, slowly creating an opening for new forms to emerge.

A series of scandals in the 1980s rocked the formerly impenetrable integrity of the Thai religious clergy (*sangkha*) (Jackson 1989). Several monks were implicated in fathering children, and then using monastic funds to bribe women into silence. It was

revealed that abbots of temples had unmonitored discretion in the use of temple funds. Some abbots had free reign over hundreds of millions of baht (tens of millions of US dollars). For the first time, monks were accused of entering the clergy for personal material gain. Others accused the clergy of being locked in rigid structure and hierarchy, unable to adapt to changes in modern society. As people lost faith in the traditional clergy, reformist movements began to arise: the mystic Huppa Sawan; the commercial and proselytizing Dhammakaya; and the fundamentalist Santi Asoke. These movements rushed into the openings created by the eroding power of the Buddhist clergy (Santisuda 2001).

The destabilization of traditional religious and military power formed the political landscape of the early 1990s. It was into this context that the second cataclysm of Thai politics landed. As traditional power structures eroded, the primary ideology that rushed to fill the gap was materialism and big business. Thailand's economy boomed, fueled in part by American war investment and by Bangkok as the new hub of urban business stability in Asia. Successive governments became more democratic, and power slowly began to shift from the military to elected officials, who stood at the top of immense business empires. Eventually, the shift in power became explicit and members of parliament began to argue for diverting military funds to economic development and for opening the long-unquestioned secrets of military budgets. Elected officials decided to shift the share of the "spoils of office" (Murray 1996) into their coffers, and to slowly replace military and civil bureaucrats with elected positions.

The military became upset at its waning power. In February, 1991, Army Commander Suchinda Kraprayoon overthrew the democratically elected government of

Chatichai Choonhavan. The justification for the coup was the familiar refrain in Thai politics – to protect the triumvirate of traditional power in Thailand, “King, Nation, Religion.” The military government revoked the constitution and replaced it with a document that would shift power back to the military.

In May, 1992, 200,000 pro-democracy protesters took over the central field in old Bangkok, planning a march to the Government House to oust Suchinda from office. At a bottle-neck bridge near Democracy Monument, the army barricaded the protesters’ path with barbed wire and fire trucks. When the protesters surmounted these barriers, the army fired with M16 machine guns. They clubbed protesters and arrested thousands. Over the following days, the protests relocated and grew up again, and again the army responded brutally. Overall, 3,500 arrests were made and most of those arrested were tortured. 52 deaths were officially acknowledged, with many hundreds of unexplained disappearances.

Images of the brutal military crackdown hit the domestic and international media, largely because Bangkok’s black market in bootleg video facilitated rapid distribution of images that could not be censored by the government (Klima 2002). The pressure on Suchinda, both domestic and international, was overwhelming, and Suchinda was forced to resign, declare amnesty for protesters and rescind the constitutional changes.

But for the pro-democracy, reform-minded in Thai society, this was not nearly enough (Murray 1996). The appearance of protests against the government was more than a revival of the conditions in the early 1970s. By the 1990s, Thai bureaucracies and civil society organizations were full of former student protesters, now professionals in positions of power. The distribution of irrevocable images of military massacre

galvanized both Thais and the international community into overwhelming political will for structural change. Like in 1973, a vacuum had opened in Thai politics, but this time, ranks of activists who had been lying in wait sprang into action. The assemblage of elements that rushed to fill this vacuum was dramatically different from the 1970s. Activists had matured with time. They had gathered global ideas about democratic governance, about civil society's role in social change, about human rights and about religion adapted to modern life. In short, they had spent twenty years gathering ideas about how to transform the traditional power structures of Thai society, twenty years spent ascending the ranks of those structures. They were thus much better equipped to enact change.

### **Buddhadasa and the Uses of Death**

In the midst of all of this social change, the revered teacher and social activist Buddhadasa Bikkhu was aging and becoming ill. He continued to speak out on social issues, especially on the dangers of the growing consumerism that was sweeping in to replace religion in Thailand. But he worked almost exclusively from his forest monastery in Southern Thailand. At the core of his teachings had always been the word dharma (*thamma*), usually referring to the teachings of the Buddha, but reconfigured by Buddhadasa to return to its Sanskrit root, meaning 'nature.' Nature is the truth of existence, the way-things-are. Our job as humans is to face this nature, not to run from it.

Following this idea, Buddhadasa stated in public sermons and in several informal written documents that death is an important part of nature and he did not want to deny it. He wanted to die at his forest monastery, without trying to prolong his life with

technology in the unnatural environment of the hospital. As he fell ill, he also spoke more frequently of his own coming death, and how he was not afraid of it. He said to a lay follower: “The Buddha attained enlightenment when he was eighty years old, and I am already eighty-seven. I don’t know why I’m still alive. It’s not good to live longer than the Buddha.”

The next day, he suffered from a left-hemisphere stroke and fell into a coma from which he never recovered. The doctor on duty at the monastery rushed Buddhadasa to the provincial hospital, where he was placed on a mechanical respirator and admitted to the intensive care unit. Some of his followers were uncomfortable with this turn of events, because the teacher had often said he did not want to be on artificial life support. Others disagreed and argued that it was their duty to give the teacher life. Once the ventilator was placed, no one wanted to be the one to withdraw the respirator because they could not shake the feeling that removing it would be killing. The negative merit (*pāp*) accrued from killing the venerable teacher would be overwhelming. But Buddhadasa’s disciples agreed to take the teacher back to his forest monastery.

Upon hearing of Buddhadasa’s stroke, King Bhumipol offered to have a Royal Thai Air Force plane fly to southern Thailand to bring Buddhadasa to Bangkok for advanced medical treatment. The King was a student of Buddhadasa’s teachings, and hoped that he could save the revered monk “to teach the Thai people a while longer” (Jackson 2003). This was also a political move by the King, whose power still rested on affiliation with the spiritual authority of famous monks. Conflict erupted among Buddhadasa’s disciples over the King’s offer. Buddhadasa had left no official written advance directive, and even if he had, at that time there was no legal or conceptual

backing for the validity of such a document in Thailand. The argument, then, rested on disciples' various interpretations of Buddhadasa's teachings, and the teacher's vague prescription that his treatment at the end of life should "be in accord with the principles by which he lived" (Jackson 2003). The teacher's disciples found themselves quickly polarized along lines following Buddhadasa's long-standing love-hate struggle with Thai "culture." The teacher had spent much of his career fighting against the "superstitions" in Thai Buddhism that obstruct people from seeing the truths of nature. Those who argued against medical care accused their peers of clinging to a misguided cultural notion that giving high-tech medical care was a form of giving life and accruing merit (Santikaro, personal correspondence).

Upon hearing of Buddhadasa's stroke, a neurologist from the prestigious Siriraj Hospital in Bangkok flew to southern Thailand to convince the teacher's disciples to pursue medical care. According to one of Buddhadasa's disciples, the neurologist "promised that they would cure Buddhadasa and return him to full health," at best an exaggeration and at worst a lie (Santikaro, personal correspondence). Armed with this added persuasion, those disciples arguing for continued high-tech medical care prevailed, and they agreed to have the King's plane fly the teacher to Bangkok on the condition that he was not to undergo surgery or other aggressive treatment.

Buddhadasa spent six weeks in the intensive care unit (ICU) at Siriraj, during which time he received several semi-aggressive treatments, including a tracheotomy and the placement of a pulmonary catheter to monitor pulmonary blood pressure and lung function. Three of Buddhadasa's disciples who had gone to care for the teacher in the hospital, including two who had originally supported moving the teacher to Bangkok,

quickly came to feel that the teacher “had already passed away,” and that the care he was receiving was clearly against what he would have wanted. The disciples, however, had been removed from authority to determine Buddhadasa’s care, which lay staunchly in the hands of Buddhadasa’s doctors, and particularly the head of the case (*jao kāwng* – lit: owner). The three disciples developed the impression that the motive for bringing the venerable teacher to receive medical care was largely political. Siriraj had been waning in prestige rankings and some felt that the teacher was kept in the ICU to keep Siriraj’s valiant efforts at the forefront of media coverage. The disciples were repeatedly locked out of decision-making about the teacher’s care and given incomplete and overly optimistic reports about his prognosis. When confronted about specific medical information, several doctors caring for the teacher said that they had never been questioned about their medical decisions, and were accustomed to behaving paternalistically toward patients and their caretakers. They refused to answer. Buddhadasa’s disciples eventually felt so embattled that they considered asking the King to intervene and allow them to return Buddhadasa to his monastery, but instead settled on writing a public letter to Buddhadasa’s doctors explaining why the teacher would not want the current care (Santikaro 1993).

Eventually, the press about Buddhadasa’s case turned negative. Doctors from other hospitals began to speak out about the treatment of the teacher. In particular, Dr. Prawet Wasi, a famous doctor, social activist and philosopher, said that the current treatment violated Buddhadasa’s teachings on death, particularly on the idea of “dying before dying,” of letting go of self to the point of not clinging to life.

The administration of Siriraj Hospital quickly changed course, and Buddhadasa was flown by Royal Air Force to his monastery. One of his disciples withdrew the mechanical respirator and the teacher died quickly without regaining consciousness.

In the months and years after Buddhadasa's death, conflict raged in the Thai press. The teacher, many argued, was an example of a perfect human being, someone who had attained ultimate wisdom through meditative practice. His level of mind was the highest that could be attained below the Buddha's. Who else could be more prepared to decide his own fate at the end of life? How did it come to pass that his clear wishes were ignored and that the Thai people clung to his life despite his teachings on letting go of a permanent self?

The teacher's death spun into broad domains in religion, politics and civil society. Buddhist reformers argued that medicine had become consumed with the disease of materialism, fighting the truths of nature with technology and greed (Paisal 2006). Many argued that personal ego and desire for prestige had pushed doctors and administrators to use the teacher's death for private gain (Prawet 1993). Others argued that Buddhadasa's lack of self-determination at the end of his life reflected a deep lack of rights possessed by the Thai people (Anothai 2002).

From July 1993 to mid-1997, dozens of seminars were held to discuss the issues surrounding Buddhadasa's death. Many of the prominent figures attending these seminars were the same individuals involved in the political machinations following the massacres of 1992. Dr. Prawet Wasi wrote a book encapsulating the conflicts arising from Buddhadasa's death (Prawet 1993). At the time that the book came out, Dr. Prawet was also the chair of the early forms of the National Human Rights Commission, and thus

deeply involved in the insertion of human rights language into the constitution (Klein 2001). Other attendees included prominent social activists in Buddhist reform, including Phra Paisal Visalo, a disciple of Buddhadasa's who had made a name for himself translating Tibetan teachings on death and dying in Thai. Many called on him to participate in the seminars. Doctors and nurses were also deeply involved in the discussions. Buddhadasa's death had revealed deep rifts in the medical system, and became a rallying point for those who wanted to transform it.

Death had arrived to Thai politics and religion. Or more precisely, dissatisfaction with death had arrived. This dissatisfaction became a rallying point for reform. Because of the massacres of 1992, and the destabilization of religious power, Thailand found itself in the midst of dramatic social change. A space had opened in religion and politics. In the middle of this space, temporally and conceptually, Buddhadasa died. And so the elements that rushed to fill this space began to assemble themselves around his dissatisfying death. And as they assembled, they disputed the rightness of his death. In its place, they began to craft a new object, a better kind of dying. This new object became known as the "end of life."

### **Death Becomes the End of Life**

Death has long been an important object in Thai thought and experience. When the politics around Buddhadasa created a space for a new kind of death, the transformation was performed on a venerable set of ideas, drawn out of a religion long concerned with death.

“Death serves two functions in Buddhism,” explained Phra Dhammavidu, a British monk assigned to teach foreign meditators at Suan Mokh, Buddhadasa’s monastery. “Death is about disgust and about fear.”

Phra Dhammavidu was given the job because he spoke English, and because he could be counted on to transmit Theravada Buddhist doctrine faithfully. His monologue on death came unsolicited, as part of a teaching on how to build concentration (*samadhi*) in meditation.

“The disgust,” he expanded, “is an antidote to lust; the fear is an antidote to laziness. Imagine sitting in meditation and there is an amazing thing that keeps coming into your mind. First it is the line of a fellow meditator’s clothes, then it is a body part, then before you know it’s a whole pornography in your head, and your meditation is completely shot. It is just so *pleasant* to follow it along, how could you not?”

“But all you have to do is think of death. I was walking through a village the other day, and there was a dog in the road that had been hit by a car. It was so disgusting, it’s head and abdomen had cracked open and guts were everywhere. Flies and maggots were eating it.” He paused for effect, and for the moans of disgust to die down. “I know,” he continued, “it’s disgusting, think about it. As soon as you think of it, all of your lust will vanish.”

Death appears in the Pali Canon<sup>24</sup> in only two forms: as a source of repulsive disgust that teaches us the impermanence of all things and thus liberates us from ego, lust and desire; and as a source of fear about the brevity of each lifetime and thus as an incentive to diligently meditate with the time that remains. Both of these conceptions of

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<sup>24</sup> The original writings of the Buddha’s disciples, upon which Theravada Buddhism almost exclusively relies.

death are part of daily life in Thailand, but in different ways. Most Thais have been exposed, through schooling, and through exposure to the Thai monastic system, to the five major categories of Buddhist concentration meditation:

- (1) *Kasina* – meditation on mental devices, including the elements (earth, water, fire, air/wind), colors (blue, yellow, red, white) and abstract images (light, space/consciousness);
- (2) *Brahmavihara* – meditation on and cultivation of the sublime states of mind, including lovingkindness (*metta*), compassion (*karuna*), sympathetic joy (*mudita*), and equanimity (*upekkha*);
- (3) *Aruppa* – meditation on the four formless spheres, or immaterial states, including infinity of space, infinity of consciousness, nothingness and the transcendence of perception;
- (4) *Anussati* – recollection or constant mindfulness of aspects of reality, including the Buddha, *dharma* (teachings), *sangha* (monastic order), morality, liberality, Deities, death, the body, breath and peace.
- (5) *Asubha* – meditation on foulnesses, focused on contemplating corpses at ten different stages of decay, described as bloated, livid, festering, split, gnawed, mangled, mutilated, blood-stained, worm-infested and skeleton (Payutto 2003, Vajiranana Mahathera 1975).

This last category is the most striking – meditating either over actual rotting corpses, or using photographs of corpses. Although most Thais have heard of this type of meditation, it is usually dismissed as an esoteric practice for monks in advanced stages of meditation and at particular monasteries. Much larger in most individuals' consciousnesses is the mindfulness of death, *maranassati*, one of the ten *anussati* meditations. Mindfulness of death (*maranassati*) is a central topic for most Buddhist sermons, including general teachings by monks and official sermons delivered at inauspicious (*awamongkol*) ceremonies, such as funerals. Rarely is a sermon delivered without at least a short mention of the fact that life is short, death can come at any

moment, and thus one must practice and attain wisdom without further delay because soon it may be too late.

Many temples distribute pamphlets with teachings explaining mindfulness of death (*maranassati*). One such pamphlet by the famous teacher Plien Panyapatipo, explains that mindfulness of death is a cure for the curse of heedlessness. “When people are young,” he explains, “they mistakenly believe they are young forever. When they are middle-aged they mistakenly believe that they are strong and do not need to go to the temple... as a result, they do not go to the temple, listen to Dharma talks, observe the precepts or practice meditation... As such, they have wasted their entire life and lost all opportunity to bring virtue and worth into their life... Birth in the next life will not be fruitful” (Panyapatipo 2007). These heedless people misunderstand the nature of human existence because “death might come at any moment. Our bodies are impermanent and their nature is to fall apart.” Thus we should practice meditation and acquire wisdom, almost as an emergency.

A second major feature of death in the Buddhist canon is as the moment of transition to rebirth. The soul and body are divided into five separate components, known as khandhas, or aggregates: matter, sensation, perception, volition and consciousness.<sup>25</sup> The three mental aggregates (sensation, perception and volition) are the product of the interface between matter and consciousness. When a person dies, their consciousness ceases its interface with matter (*rūpa*), including the body. Thus the mental aggregates disappear (Anuruddha et al. 1993). Disembodied consciousness persists after

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<sup>25</sup> The aggregates are (in Pali Romanization): *rūpa* – form or matter, including the material body, the physical sense organs and the outside physical world; *vedanā* – sensation or feeling, which determines whether an object is received as either pleasant or unpleasant; *saññā* – perception or cognition, which registers whether an object is recognized or not; *sankhāra* – volition or mental formations, including all types of thoughts and compulsions; *viññāṇa* – consciousness or awareness (Buddhaghosa 1997, Keyes 1987a).

death and is eventually reunited with another body, creating a new set of mental aggregates. Throughout life and between lives, both matter and consciousness constantly transform. The mental aggregates, which arise at the interface of the morphing consciousness and matter, transform as well. Thus there is no constant self. Personhood is contingent, malleable and constantly changing.

For most Thais, the key to this set of metaphysical principles is that the moment of death determines the outcome of rebirth. The content of one's consciousness (*winyān*) at the moment of death is a large part of the karma (*kam*) that is still stuck to a person's consciousness, and it is this karma that causes the consciousness to be reborn again into a new body. This is why Fawng's children whisper the sacred word *phuttō* into her ear as she is dying, and why they tell her to follow the orange corner of the monk's robe. They are passively filling her consciousness with positive thoughts, full of merit that will direct a positive rebirth. And this is also why her children gather her things around her head so that her consciousness will not cling to objects that she misses and thus contain negative karma when she separates from her body.

Prior to the social changes of the 1990s, then, death has had two major features for most Thais. First, it was a concept to be contemplated by the living as a tool for spiritual practice. And second, it was an object, a thing, a moment in time. The wisdom that could be attained from it had nothing itself to do with dying. One could think about death to fight lust, or to become motivated to practice. But of the experience of dying, only the exact moment of death mattered.

Buddhadasa's death, and the political and religious context into which it fell, made it clear that this concept of death was inadequate. It was the decisions made in the

last months of Buddhadasa's life that launched Thais into debates about great rifts in Thai society. No one doubted that Buddhadasa's mind was perfect at the moment of his death. They doubted the decision to circumvent his self-determination about health care at the end of life. This doubt became much larger than the Saint's death. Because of the conflicts in religion and politics in the 1990s, because of the resultant opening in Thai society, an assemblage of elements began to come together to propose changes to Thailand. And as they assembled, they took up their dissatisfaction with Buddhadasa's death as the centerpiece of their arguments. They began to operate on the idea of death, and to craft a new idea to replace it. The new idea took on the name "the end of life," a period of time that required knowledge and decision-making, that needed to be experienced and studied, a period of time that needed to be crafted to reflect the ideals of a reformed Thai society. And around this new idea, a set of ethical frameworks began to emerge, frameworks that have ended up in Kiang's hospital room, colliding with the standing ways of approaching death.

The concepts are still forming and malleable, still being negotiated and renegotiated in the contemporary moment in which Kiang's hospital room lies. But they have begun to coalesce into two related ethical frameworks. At the heart of each framework is a figure, an imagined new Thai person, an ideal way of being that embodies reformists' vision for a transformed Thai society. The first is the figure of the dying patient as a rights-wielding citizen, who uses the end of life to become politically empowered. This is essentially a political figure, emerging from Buddhadasa's problematic death in the midst of the political conflicts of the 1990s. The second figure is of the dying patient as a seeker of wisdom, a person who uses the experience of the end

of life to face the truths of nature. This figure is a spiritual and religious figure, emerging from Buddhadasa's problematic death in the midst of the religious turmoil of the 1990s. The two figures are intimately intertwined. They are both knowing subjects. And they both become manifest in a new period of time. They both come to be by knowing and understanding not only death, but the new emerging object, the "end of life." But the figures are also different from one another in crucial ways. The figure of patient as rights-wielding citizen involves a political engagement, a sense of individuality opposed to family members and healthcare providers. Contained in this figure is a transformation proposed for Thai society – a transformation not so much about experience or thought, but about rights and decisions. The figure of patient as seeker of wisdom, on the other hand, involves a new and internal approach to the *experience* of dying. It does not concern medical decisions or power dynamics, and so it is not about rights. Instead, it proposes a spiritual way of being, a way of facing the truth of suffering and using it to improve the mind.

In the 1990s, Buddhadasa's death landed in an opening in Thai politics and religion created by the destabilization of traditional power structures due to a confluence of historical events. And in the decade after his death, two ethical figures emerged to fill this opening. What produced these ethical figures? How did they come to orbit death and dying as their focus? And how did they make their way into the ethical world of the contemporary deathbed, into Kiang's hospital room?

## **Chapter Four:**

### **Patient as Rights-Wielding Citizen**

The sign on Kiang's wall reads: "Things you have a right and responsibility to know during your stay in this hospital: your disease, treatment you are receiving for your disease, and self care appropriate for your disease." The sign, as a stand-in for a set of policies, has a vision of Kiang as a certain kind of patient, a rights-bearing and rights-wielding citizen, a knowing subject rather than a passive object of health care.

The sign is a condensation of ten patient rights passed in 1998, not by legislation but by a voluntary act of the healthcare professional councils – medicine, nursing, dentistry, pharmacy and the associated medical arts. A poster with the full ten rights is posted in the head offices of the hospital, and a similar list appears in the hospital accreditation manual, and in a "guide to patient rights" distributed to all health workers in the hospital. It reads:

#### Announcement – Patient Rights

In order to establish a relationship between healthcare professionals and patients based on a foundation of mutual trust and understanding, the Medical Council, the Nursing Council, the Pharmacy Council, the Dental Council and the Committee on Medical Arts come together to establish the following patient rights:

- 1) All patients have the fundamental right to receive healthcare according to the Constitution of Thailand;
- 2) All patients have the right to receive services from healthcare professionals with no discrimination according to class, race, nationality, religion, society, political affiliation, gender, age or disease characteristic;
- 3) *Patients who seek medical care have the right to adequate information and clear understanding from healthcare professionals so that they can choose to accept or refuse treatment from healthcare professionals, except in the case of urgent or necessary treatment;*
- 4) Patients in life-threatening situations have the right to receive timely treatment from healthcare professionals appropriate to their case without need for the patient to request or refuse the treatment;
- 5) Patients have the right to know the first name, last name and specialty of the healthcare professional providing services;

- 6) Patients have the right to ask for opinions from healthcare professionals other than those providing treatment, and have the right to change service provider and location;
- 7) Patients have the right to the strict protection of personal medical information from healthcare professionals, except with permission from the patient or following legal duty;
- 8) Patients have the right to complete information in deciding to participate or withdrawal from being a research subject in research conducted by healthcare professionals;
- 9) Patients have the right to information about medical care from their own hospital record only when requesting this information does not violate the personal rights of anyone else;
- 10) Parents or surrogate decision makers may use rights in place of patients who are children under 18 years of age, physically disabled or mentally disabled and cannot use their own rights.

But of the ten patient rights, only number three appears on Kiang's wall: the right to "adequate information and clear understanding," reformulated on Kiang's wall as the "right to know your disease, treatment you are receiving for your disease, and self care appropriate for your disease."

When I asked about this difference, and about the origin of these rights, everyone at the hospital deferred my question. "You should go to Bangkok and talk to the Medical Council," they told me. The Medical Council of Thailand (*phāet saphā*) was the pioneer in creating the patient rights, and the Secretary General at the time of passing the rights was a member of a political action group known as the Rural Doctors Association (*chomrom phāet chonabhot*). My quest to understand Kiang's wall thus led me eventually to the office of Dr. Wichai Chokwiwat, founder of the Rural Doctors Association, the man most responsible for the birth of patient rights in Thailand.

We sat in his office at 7pm, after hours, in an out-of-the-way building at the Ministry of Public Health. When I had asked for an interview, I had told him I was trying to find the origins of the sign in Kiang's hospital room. He was clearly eager to explain, and he added me after hours to his busy schedule, and we met after the building was

already shut down. He began his story at a familiar place, the galvanizing protests of the 1970s.

“Rural doctors were part of the protest movements in the 1970s,” he began, “because they had been out in the countryside, and they knew how much the poor suffered.” Dr. Wichai was animated, a sprightly, elfish older man. And this was clearly a topic he wanted people to understand.

“At that time, there weren’t enough doctors in rural areas,” he explained. “One doctor had to care for maybe 80,000 people, and there was so much suffering that we couldn’t help. I remember when I was a doctor in a rural area, and saw 200 patients a day, and had to do everything – surgeries, everything. And the people were so sick because they were poor, and the government did very little for them.

“After the crisis in the 1970s, we knew we had to change things from the inside. So we founded the Rural Doctors Association (*chom rom phāet chonabot*), and we decided to run for the elected positions at the Medical Council. At first, we won only two of the twenty-five seats. But after two more terms, we were able to win a majority. It took ten years, but we took over the Council. Then for ten years, our group’s members took turns serving as Secretary General of the Council.”

Dr. Wichai was placing himself squarely in the history of Thailand. He and his fellow rural doctors were driven to join the students in the 1970s demonstrations. And like the students, when the military cracked down on the protests, the surviving rural doctors dispersed back into professional career tracks, slowly working from within the system and biding their time to effect change.

“But we knew that policy was not enough,” Dr. Wichai continued, and I perked up, knowing that this was the real beginning of his story, “because the main problem with the poor was that they did not feel like they had any power. When they went to see a doctor, they thought of the doctor as a God (*phrajao*) and of themselves as poor and powerless, and so they did whatever the doctor said. Doctors could do anything, or harm the patients, and the people did what the doctor said.”

“So you felt,” I asked, “that doctors were part of the problem of what was making people so poor and powerless in the rural areas?” I was genuinely confused by Dr. Wichai’s train of thought. His narrative began with doctors aware of the plight of the poor, helplessly trying to plug up the holes in the system to keep the floodwaters of suffering at bay. But then he shifted to explaining the dire need to empower patients in the face of powerful doctors. Almost all doctors in Thailand are required to serve an initial period in a rural hospital as an indentured payment for their free medical education, so I wondered about how doctors could be divided this way.

“There are many kinds of doctors,” he said, smiling kindly at my naïveté. “The rural doctors saw the suffering of the poor, but most doctors ran away from the rural area to be specialists in the city. But this is not really what we were doing. The important thing that the rural doctors realized was that in order to have real power and improve their poverty, the rural people need to have rights, and they need to know that they have rights and know how to use them.”

Already, after five minutes in Dr. Wichai’s office, an ethical figure was beginning to emerge from his explanation, the ethical figure now coming to land in Kiang’s hospital room. The motive force beneath all of Dr. Wichai’s activities was the urgent political

need to make rights-bearing citizens out of the disempowered rural poor. Medicine and the political muscles of the Medical Council were simply the mechanism for transforming Thais into rights-wielding individuals.

“How did you do this?” I asked.

“We set up a sub-committee of the Medical Council, and for three years, we had many discussions and wrote many drafts, and during this time, we mostly studied the patient rights of other countries like the UK and the US, and eventually we chose ten patient rights to establish in Thailand.” He was referring to the list of rights that appeared in the documents of Nakhon Ping Hospital.

Pushing Dr. Wichai on the dates of all of these activities, it was clear that the 1980s were a time of discussion and foment, a time when his group of rural doctors drew mostly on international sources to build an argument for patient rights. Their group had turned to rights as the way to empower the poor, and to international sources to establish these rights. They knew from experience that they needed a global ideological backing to make their agenda irrefutable.

Then, after the student protests in 1992 and the brutal military crackdown on the students, Dr. Wichai’s group found themselves in the vacuum of political power left behind by the destabilization of old forms of Thai power. And they knew from experience after the 1970s that such an opening would not last. The brutal violence of the 1970s had created sympathy for a time, but it had quickly dissolved in the face of powerful conservative political structures in Thailand and had done nothing to prevent a repeat of the violence in 1992. Something fundamental needed to be done, something that would permanently fill the opening with a liberal ideal. To accomplish this, they

reached for the language of human rights, a powerful global ideology that they hoped could help establish some institutional structure to their agenda. A new constitution was pushed through parliament in 1997, and sets of activists from all professions pushed language into it, so it was ultimately filled to the brim with the language of human rights, drawn from international sources. This document was a novel form of ethics imported into Thailand to support one agenda for what should fill the sudden opening left by destabilized power structures.

“All our group did,” said Wichai, “was bring the human rights in the constitution into the medical profession.” Once the constitution was full of human rights language, no one could protest importing that language into the professional institutions, which for medicine meant patient rights.

But this was not enough. Wichai and his group, along with similar groups in other fields of Thai society, knew that words in a government document do nothing as long as the military and old land-owning elites can continue to wield the actual power. What were needed were not simply rights, but rights-bearing citizens. Thais needed to be transformed. Thai culture needed to be transformed.

“People needed to know that if doctors violated their rights,” explained Wichai, “they should hold the doctors responsible. So our rural doctors group exposed cases in which doctors had been bad and harmed the people.”

Since they were in control of the Medical Council, the rural doctors were privy to all medical law suits brought against the doctors in Thailand. Wichai’s group helped to establish an outside NGO known as the Consumer Foundation (*mūnniti phēua phūboriphōk*), and then they selected one case for each of the ten patient rights they had

established, and exposed those cases to the press, using the Consumer Foundation as an advertising and patient-education body.

Of all ten patient rights, Dr. Wichai brought up the example of the right to knowledge, which he quoted to me from memory:

Patients who seek medical care have the right to adequate information and clear understanding from healthcare professionals so that they can choose to accept or refuse treatment from healthcare professionals, except in the case of urgent or necessary treatment.

Dr. Wichai removed a book from his desk and handed it to me. It was a publication from the Consumer Foundation (Tatsanee 1999) with the ten exposed cases. He turned the page for me to look at the case concerning the right to knowledge:

Mr. Chalaw was in his 60's. He was a farmer, which did not help him to good health in old age. Mr. Chalaw still needed to work, but his body was naturally deteriorating. His vision had become cloudy, and he knew that something might be wrong with his cornea. He needed to go see the eye doctor urgently.

Not wanting to bother his children and grandchildren with the distance, he went alone. After examining Mr. Chalaw, the doctor gave the opinion that he had a cataract in his eye. Mr. Chalaw would need surgery to put in an artificial lens, and would have to pay the expensive fee for the surgery. Dr. Chalaw informed the doctor that he did not have much money, and asked if he could instead just eviscerate the eye to get rid of the cloudiness. [...] The doctor did not answer and was not interested in what Mr. Chalaw had to say. Instead, he told Mr. Chalaw to come back in a month for treatment.

Mr. Chalaw returned to the hospital again alone because he understood that the treatment would be completed in one day. [...] He understood that he was not coming for a lens, but just to eviscerate his cloudy eye. After the surgery, Mr. Chalaw instead found out that he had received a new lens at the price of 6,200B (\$250).

Mr. Chalaw had no money. His children and grandchildren had no money, and they tried to take out a loan to make the payments, but they could not raise the money in time to pay. The doctor told Mr. Chalaw to return to the hospital for a second surgery to take out the lens.

The book in my hand was entitled “Patient Rights: Studying and Understanding How to Use Them.” It included the cases that had been exposed to the media – one case for each patient right – and instructions to the public for how to respond to them. Their instructions for Mr. Chalaw’s case were:

Mr. Chalaw told the doctor that he had no money and that he wanted only an evisceration surgery. [...] But the doctor did not listen to Mr. Chalaw’s request, because he was used to being the one to make decisions, and he didn’t think that the cost of the surgery was very significant. He thought that Mr. Chalaw would be able to come up with the money.

But in the end, even though the doctor violated Mr. Chalaw’s rights and made him undergo a second surgery, the old man did not think about it much because his problem was solved. This story would have disappeared if the newspapers had not publicly denounced this deplorable conduct.

We should help health professionals by doing our duty and using our right to know: what is our illness? how should we take care of ourselves? what is the best treatment? what are the likely results of treatment? If we need to choose a treatment, we should ask until we understand. If medical professionals are violating our rights, we should inform them that we know our rights.

The take-home message from the Rural Doctors Group and their partner the Consumer Foundation was clear:

We [ordinary people] should do our duty. We should use our rights. We should make sure that the other side [health professionals] know what rights we have. We should teach them to respect our rights to the same degree that we hold [health professionals] up and honor them. At first it may seem difficult, but with frequent practice, both sides will get used to it and it will become natural.

The Rural Doctors Association, and their ally the Consumer Foundation, were in the business of making rights-bearing citizens out of the powerless Thai poor, and they were using medical care as their home base for this transformation. In this project, they were clearly one spoke in a much larger movement that began with the student protests in the 1970s. They carried the spirit of those protests onward quietly into a battle for the

Medical Council in the 1980s. In the early 1990s, the massacre of protesting students launched previously dormant activists in the various professional fields into action to push human rights language into the constitution. As a part of this thrust, the Rural Doctors leveraged their power in the Medical Council to transfer human rights into health care institutions. Simultaneously, they launched an ambitious project of subject-making, hoping to teach rural Thais to think of themselves as owners of their own bodies, as rights-bearing individuals with power relative to institutions of power. This education movement shifted the focus from policy to subject-formation. A figure had been created – the figure of an ideal Thai citizen, using illness as a site to exercise inalienable democratic rights. But rather than leave this figure to policy, the Rural Doctors wanted to go to villagers and teach them how to become this ideal citizen.

As with all sectors of Thai society at the time, the conservative counter-response was dramatic, but incomplete. Because of the political outcry against the massacres and the brilliant move by activists to equate human rights with freedom from violent tyranny, conservatives could not argue against turning Thais into rights-bearing citizens. They were left instead to argue against the relocation of certain forms of power into citizens' hands. In medicine, this counter movement was led by Dr. Somsak Lolekha, another senior member of the medical council. He felt that the Rural Doctors' strategy would do nothing more than teach Thais to mistrust doctors or to make them greedy for money from law suits and would thus ruin the doctor-patient relationship. In this way, his arguments mirrored, in a professional context, the arguments in Thai politics about the need for a strong, paternal state.

Dr. Somsak launched a counter-campaign to take back the Medical Council, to transform the Council into a body that could protect doctors from the onslaught of lawsuits that would be caused by patients wielding their newfound rights in embattled blame of doctors' faults. By the early 2000s, his group succeeded, and squeezed all members of the Rural Doctors Group off of the Council.

When I contacted Dr. Somsak, still Secretary General of the Medical Council, he was eager to share his side of this story. In the first minutes of our interview, he mentioned the Rural Doctors Association. "Those people are the enemy," he said. "Their organization is not 'rural doctors,' it is 'doctors against doctors.' The cases that they published were wrong and blamed doctors. So many cases were wrong, too, see..." He reached into his desk and withdrew the publication from the Consumer Foundation. "There was a case of a man with a cataract," he said, and pointed in the book to Mr. Chalaw. "A patient came in for a lens operation, but he could not pay. The NGO claimed that the doctor removed the lens because the patient could not pay, but I remember this case, the doctor said that he had to take it out because it was hemorrhaging and it was damaged."

"What do you think about the right itself, a patient's right to know about their disease and treatment?" I asked.

"It is good," he said, though he hesitated. I could hear something in his hesitation akin to: *who could possibly come out and say that patients should not have a right to know?* Instead he said, "Patients need to know. But the rural doctors blamed doctors for everything, they made people mistrust and hate doctors. They made doctors and patients be on opposite sides of a battle. And now people think that they can make a lot of money

if they sue doctors. When they made these patient rights, they did not make doctors' rights, and they did not make patients' responsibilities. Now we need to teach doctors that they have rights, too, and defend them against law suits. [...] The people who sue don't know anything about medicine, how can they know what was a mistake or not? They sue because they think they can make money or because they think that doctors are bad people. That is all because of the Rural Doctors Association."

I talked to Dr. Wichai about Dr. Somsak's perspective, and his counter-response to it was equally vitriolic. "The doctor-patient relationship is bad because the Medical Council wants to defend doctors no matter what, and never protect patients. They are more like a union than a council." The tug-of-war between the Rural Doctors Association and the current Medical Council is a battle about transferring real power to the hands of rural citizens versus keeping power in the paternalistic hands of doctors. It is a microcosm of the battle in Thailand over the nature of the Thai nation-state.

The validity of a rights-discourse itself is not in question on either side of this struggle. Rights themselves are beyond dispute. Groups of activists took advantage of the vacuum of power in the 1990s to draw human rights language into the Thai constitution, and then into professional organizations. Their plan was ingenious and effective, and the political landscape shifted so that no one could argue for the removal of these forms of thought from Thai politics. The struggle between Dr. Wichai and Dr. Somsak, then, is not a struggle about the appropriateness of a rights discourse for Thailand, it is simply a struggle about the contents of those rights. It is thus an engine, on both sides, that drives Thailand deeper and deeper into the ethical figure of the Thai patient as a rights-bearing and rights-wielding citizen.

In my interviews with Drs. Wichai and Somsak, they both spontaneously brought up the right-to-know as the exemplar right for understanding the stakes of their debates. The parallel between their selection and Kiang's wall was too conspicuous for me to ignore. I asked Dr. Somsak about it.

“Well, most of these rights,” he explained, pointing to the list of ten, “are easy. Of course we will treat patients regardless of race. Of course we will keep patient charts confidential. Of course patients can go see another doctor and know our name and position. Those are all easy changes to make. But knowledge is the hard part. Knowledge is the core of everything. Do patients know enough to make decisions? They don't know anything about medicine. And then there is the issue of... heart power...” he paused to see if I would catch the vocabulary word. I nodded, and he continued. “Some patients will give up (*mot kamlangjai*) and die faster if we tell them everything.”

“Do you think that there are cases where patients should not have a right to know?” I asked.

“No!” he replied. “Patients have to know. It is their right. We need to change Thai culture about this. We need to teach doctors to be skillful in giving bad news, and we need patients to be able to handle the news. Everyone has a right to know, we just have to figure out how to tell them.”

Dr. Wichai and Dr. Somsak are at the helm of opposite sides of a political battle raging in Bangkok, a small microcosm of the political battles raging over the nature of Thai politics. In their particular civil society domain, medicine, this debate plays out in the form of professional-client relationships, rich-poor dynamics, and the urban-rural location of power. Out of this battle, a coherent ethical figure has emerged, the figure of

a Thai patient who wields the right to know and is the right kind of citizen-subject. This figure is not simply a potential, it is a persuasion. According to Somsak and Wichai, Thai culture needs to be changed. Thai patients need to be changed into the kinds of patients who know about their illnesses and wield this knowledge as a right to decide about their own treatment.

Of the patient rights at the core of this newly emerging ethical framework, one right is at its core: the right to knowledge. And the heart of the right to know is not about knowledge in general, it is about “giving bad news” and “dying faster.” The activities of the Rural Doctors Association gathered momentum throughout the 1980s, and by the early 1990s they had coalesced into frequent academic seminars, mostly consisting of reviews of important patient rights cases from Europe and the United States. Of these cases, academics stayed away from particular disease or condition-specific rights, and chose instead to import general principles. This changed, however, after Buddhadasa’s problematic death in 1993, which spurred public debate that could not be ignored. In the same months that lawmakers were sitting down to draft versions of a constitution that contained human rights language, many of the same people attended seminars about Buddhadasa’s death.

At the heart of the Medical Council’s academic debates over patient rights was Dr. Vitoon Eungprabhanth, a doctor and a lawyer who had trained in medical law in Germany. In the first sentence of my exchange with Dr. Vitoon, I asked: “what is the most important aspect of medical law in Thailand?”

He answered: “the right to self-determination, especially at the end of life.”

When I asked why, he answered: “We had a famous monk, named Buddhadasa, who died a long death with a lot of conflict (*khon tāwsū kan*).”

I looked up from Dr. Vitoon’s desk to a poster of Buddhadasa. It was the only decoration in the famous professor’s office.

Dr. Vitoon continued: “Buddhadasa taught that people should face the truth (*khwāmjing*) of nature (*thammachāt*), and he said that he did not want to fight his death with a lot of technology. But at his death, doctors and people in the public did not listen to this, and they flew him to Bangkok and treated him in the intensive care unit. [...] The culture (*watanatham*) of patients is to be afraid of doctors, to let doctors decide everything. The culture of doctors is to fight disease no matter what, to use technology and science. [...] The end of life is the situation in medicine when doctors are most likely to violate a patient’s right to self-determination. Patients have a right to know their condition, and they have a right to decide how they want to be treated.”

Later, back at my hospital in Chiang Mai, nurses and administrators echoed this emphasis on end of life and self-determination. “No one talks about the patient rights,” explained one nurse, “except for end of life care. Then we talk about it all the time.”

Because of the coincidence of Buddhadasa’s death in the midst of a political opening in Thailand, a broad human rights movement that might otherwise have remained centered on rich/poor and rural/urban dynamics shifted instead into debates about care at the end of life. Politics colonized medicine, and used death as its focal point.

By the early 2000s, the list of ten patient rights still remained a fragment of policy. It found its way, in the form of the hospital accreditation manual, into the offices

of provincial hospitals. But it was only the end of life issue that policy makers continued to push forward until it became law. In 2008, the first legislation concerning patient rights was passed. The statute reads: “Individuals have a right to create a living will<sup>26</sup> to refuse health treatment<sup>27</sup> whose only purpose is to prolong dying at the end of life<sup>28</sup> and to end suffering from pain.”

As a result of an engine of political conflict over the locus of power in the Thai nation-state, activists pushed human rights language into the Thai constitution, and doctors extended this into the field of medicine. They produced an ethical figure, an imagination of an ideal kind of Thai citizen-patient who exercises the right to self-determination in the clinic. And because of the coincidence of Buddhadasa’s death, this ethical figure became infused with a new word, the “end of life,” the period of time when the ideal Thai patient-citizen must be most vigilant in determining his fate. The first patient right passed legislatively in Thailand specifically addresses the “prolonging of dying at the end of life,” creating a distinction between dying (*kāntāi*), death (*khwāmtāi*) and a new object that the Thai people must attend to, the end of life (*wāra sutthāi khāwng chīwit*). And as an instruction for the end of life, Thais are presented with an ethical figure, the image of the rights-wielding citizen, the ideal way of being. The new object, the end of life, is the vehicle of transformation of Thai people, Thai culture, and Thai society.

This ethical figure has arrived in Kiang’s hospital room as a sign on her wall, declaring her “right to know” her diagnosis. It hovers above her, and above me and Jae as we sit on a straw mat, discussing her mother’s ignorance in English. In Kiang’s case,

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<sup>26</sup> *nangsēu sadāeng jētanā*

<sup>27</sup> *mai prasong rap borikān sātāranasuk*

<sup>28</sup> *yēut kān tīi nai wāra sutthāi khāwng chīwit*

the ethical figure is nothing more than a gentle push on the other ethical frameworks in the room. But when I ask Jae about the sign on the wall, she has clearly thought about it. “A right to what?” she asks. “A right to know her disease, which can’t do any good, can’t be cured. A right to worry in her last days. That is not a right I want for my mother.” The ethical figure is at least enough of a presence to force Jae to form an argument against it, an argument reaffirming the ethical imperative to give life by maintaining ignorance.

In other contexts, the ethical figure of dying patient as rights-wielding citizen exerts more pressure. When Dr. Danai told Nanban that he had cancer, he said that Nanban “had a right to know his diagnosis.” Primarily, this was a moment of justification, but there was also an unsubtle persuasion in it. To be the right kind of patient, Nanban should know the truth, he should be the legal owner of his own information.

But despite these moments of subtle pressure, the figure of dying patient as rights-wielding citizen is still nascent. Although the sign hangs in every hospital room, the ethical figure itself only weakly infuses decisions, identities and experiences. I asked one doctor in the hospital about this. “The patient rights sign hangs on every wall,” I said. “But it seems like no one follows it or thinks about it very much.”

“Thai people,” he said, “like to make rules and then not follow them.”

“Do you think it is unimportant, then?” I asked.

He laughed and then suddenly looked serious. “Cultures change slowly,” he said. “That sign on the wall is extremely important. In twenty years, everything about how we practice medicine will change because of that sign. The way we communicate with

patients, the kind of medicine we practice, the role of the family in making decisions. It is a big deal (*reuang yai*).”

When I brought up the same question to Dr. Wichai and Dr. Somsak, and despite their opposite positions, their response was the same. “This way of approaching patient care is subtle now,” said Dr. Wichai, “but the change has been made, and it will transform the culture of medicine.”

A set of concepts and practices has rushed into the space opened by 1990s politics, assembling around the end of life because of the coincidence of Buddhadasa’s politicized death. One thrust of this assemblage is an idealized Thai citizen, a dying patient who wields her right-to-know as a form of political empowerment. This figure clashes with entrenched frameworks already at play in the hospital, particularly with the use of ignorance to maintain heart power and thereby give life. And because of the strength of these existing frameworks, the effects of the patient as rights-wielding citizen are still subtle, seen only in Jae’s argument for maintaining ignorance and in the conflict between Dr. Danai and Nanban’s family. But the figure is present and it has begun to gently tug on the experience of dying in Northern Thailand. And most feel that this gentle tug will end up steering ethical worlds like Kiang’s hospital room in dramatically new directions.

## **Chapter Five: Facing Truth and the Market for Spiritual Value**

### **Facing Death**

Nurse Ampha disapproved of Kiang not knowing about her pending death.

“Mother Kiang,” Ampha explained, “will have no chance to prepare her mind for the final moment.” Later, when Ampha introduced me to Mali, who was using illness as a source of wisdom for spiritual practice, Ampha said, “finally, a true end of life patient.” Ampha was not particularly concerned with Kiang and Mali as rights-wielding citizens – her agenda was not to transform them into empowered democratic subjects. She had a different ethical figure in mind for the women – a figure of the spiritual seeker who uses the experience of the end of life to attain wisdom. She was not concerned with decision-making, but with transcendence, with experience.

“I have always been interested in meditation,” Ampha explained to me one day in the hall. “In Buddhism, we teach that life has suffering in it – we are all born, get old, have pain, and die. These are natural things. If we don’t accept the truth of nature, we will suffer and be without peace when we die.”

I asked Ampha, “So have you always wanted your patients to know their prognosis?”

She thought for a moment. “No,” she said. “It is a new thing. I first heard about it from a lecture by Phra Paisal Visalo. He is the expert on facing death. There are trainings, too.”

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“In order to understand the nature of existence and be free from suffering,” explained Phra Paisal, “the most important thing is to face reality. This is true in all things. Therefore, the first requisite for having a peaceful death is to accept death, to know and accept that one is going to die.”

It was early morning, before the opening activities on the third day of a four-day training entitled “Facing Your Death Peacefully” (*phachōen kwām t̄ai yāng sangop*), hosted by Phra Paisal’s Buddhist organization, the Putigā Network (*khreua khāi putigā*). Phra Paisal and I were sitting out on a veranda overlooking a lush garden at a conference center outside of Bangkok. Though I was a participant in the training, I asked for an audience to clarify some of the history and agenda of the movement. Phra Paisal is confident and articulate and his gaze is penetratingly calm. He is one of a breed of young superstar monks rising to popularity among lay followers through scholarship and charisma. His devotees are the educated, liberal middle-class, largely Buddhists still involved in the social and practice movements of Buddhadasa.

The training, as well as the broad social agenda of Putigā, can all be understood via the word *pachōen*, to face or confront. Putigā was formed in 2001 by Phra Paisal explicitly to fill a vacuum that was being left by the wane of traditional religious power in Thailand. People had begun to lose faith in the conservative Thai *sangkha*. According to Phra Paisal, this was because the clergy remained locked in a ritualistic spirituality based on distant and inconceivable enlightenment, divorced from the real problems of modern life. Swept up by globalization and social change, people were quickly leaving the clergy behind and turning to alternative forms of spirituality. The most popular of these new movements was the consumerist and proselytizing Dhammakaya sect. Phra Paisal

worried that Thai society was falling irretrievably under the sway of consumerism as a solution to the challenges of modern life. Particularly, the growing Thai middle class, increasingly seduced by materialist values, had begun to deny the reality of existence by buying themselves comfort instead of working hard to understand the fundamental nature of being human. According to Paisal, the Buddhist critique of consumerism itself is ancient,<sup>29</sup> but the mass scale and total domination of consumerism as a way of life is a modern phenomenon and needs to be resisted.<sup>30</sup>

“Why death, then?” I asked Phra Paisal.

“Putigā became interested in death because people asked for it,” he answered. He had translated the Tibetan Book of Living and Dying into Thai, and after Buddhadasa’s death, people had begun to request teachings about it. “Buddhadasa’s death was the first time that we understood that consumerism is epidemic in modern Thai medicine, the first time that we realized how much people want to buy their way out of death, out of the truths of nature.” Putigā realized that death could become a focal point for addressing materialism in Thai society. Putigā quickly saw itself as an organizational incarnation of Buddhadasa’s social vision, both through Phra Paisal himself as a long-time devotee of the revolutionary teacher, and by addressing the root social ailments beneath Buddhadasa’s problematic death.

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<sup>29</sup> The critique of consumerism in Buddhism is generally founded on its effects on the human mind, which differentiates it from most critiques of consumerism found in the West, which rely on the effects of consumerism on equity and justice in a broader society. There are, however, interesting parallels, such as Marx’s argument that consumerism alienates individuals from their labor and from the products of their labor, implying that the suffering of man comes from alienation from concrete experience and from the social relationships that come from alienated production (Marx 1867 [1978]).

<sup>30</sup> It was also the entry of consumerism itself into spirituality and religion in the form of Dhammakaya that inspired Paisal to action. Some of this was inspired by his studies with Tibetan teachers who had begun to grapple with consumerism when teaching Western students (Trungpa and Baker 1973).

In the hands of Putigā, the word *pachōen* performs a transformation on death. The old object death is not adequate to their task, because it encourages only urgency, not understanding. Putigā wants to transform death in Thailand from a concept, whose abstract contemplation inspires either fear or revulsion, into an *experience* and a *process* that can be faced, studied, and understood. In so doing, they plan to transform Thai people from passive consumers of religious wisdom into active explorers who use the challenges inherent in life and death to understand the nature of human existence. Their trainings are a technology, designed to craft a new kind of spiritual individual.

Out of the trainings, we begin to see the shades of an ethical figure emerge, of the kind of person that Ampha wants Kiang to become – someone who faces reality, and by so doing understands the nature of existence. This ethical figure hovers in Kiang’s room.

### **The Human (*Manut*) as an Ethical Figure<sup>31</sup>**

But Ampha does not only have an ideal for Kiang at the end of life. She also has an ideal for herself. When disapproving of the approach to Kiang’s death, Ampha looks exhausted from a long work shift in the understaffed hospital, but her eyes light and her posture rights when she talks about Kiang and the coming ‘final moment.’ Thinking about it fills her with heart power. She *wants* to talk about it. She would rather spend her day preparing Kiang’s mind than writing in a chart and checking vital signs. She has a vision for herself – she wants to be a certain kind of healer, one whose job is primarily to help patients through the dark but inspiring tunnels of fear and death.

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<sup>31</sup> This line of inquiry owes a great debt to Paul Rabinow’s concept of “figures of anthropos” (Dreyfus and Rabinow 1982, Rabinow 2003)

Ampha recently attended a conference of the Hospital Accreditation (HA) Bureau in Bangkok. HA was established initially to ensure adherence to a common standard for hospitals in Thailand, focusing on sterile procedure, infection control and prescription protocols. It is in charge of every hospital in the country. This year, HA took a radical shift and dedicated half of its yearly session to a broad social change program entitled “humanized healthcare” (*rapop sukapāp thī mī huajai khwāmpen manut*). When I asked Ampha what this word “humanized” meant, she replied, “it is about finding true value (*khunkhā tāe*) in being a nurse and interacting with patients.”

When she told me this, I was unable to contain my surprise about such a broad social program coming from a public health bureaucracy, “Why is HA suddenly interested in this?” I asked.

“We are in a crisis in healthcare in Thailand,” she explained. “Everyone is afraid of being sued. We are understaffed and overworked. No one wants to be nurses and doctors anymore. They want to be business people. We need a way to make healthcare attractive again.”

Seeing my interest, Ampha passed me to a senior nurse in charge of hospital accreditation for the hospital. From her, I received a small book on the philosophy of humanized health care (Piyasagol 2005). The introduction contains the following explanation:

We can already do heart surgery and brain surgery and cure many previously fatal diseases. We know now that we need to move from that era to an era with a health system whose heart is humanity (*khwām pen manut*). This does not mean that we will abandon or lessen modernity (*tan samai*), but bring the heart of humanity into modern medicine itself. [...]

All of this follows the Royal Word (*phra rāchaprasong*) of the King Father (*somdet phra rāchabidā*), father of modern medicine, respected throughout the country, who

entrusted medical students with the command: “I do not want you to be only doctors, I also want you to be human (*manut*).”

As explained by Dr. Prawēt Wasī, being human (*manut*), at its profoundest level, is the state of entering truth (*khwām jing*), goodness (*khwām dī*) and beauty (*khwām ngām*). Other animals (*sat*) cannot enter this state. Even angels (*thēwadā*) cannot enter this state. The ability to enter truth, goodness and beauty is a characteristic only of humans. And when a human enters truth, it gives rise to freedom (*isaraphāp*), supreme health (*sukhaphāp lonlēua*), and love for humanity (*pēuan manut*) and all existence (*thamachāt thang mūan*).

If health workers enter into being human, it will have several effects. First, health workers themselves will have abundant happiness (*khwām suk yāng lonlām*). Now they are all stressed, work is hard, and they cannot take it. Everyone is afraid of being sued. If they can enter into the heart of humanity, they can reduce and eliminate their stress and be truly happy. [...]

Second, patients and families will be happy because they will have contact with health workers who have entered into truth, goodness and beauty. [...] This has been shown scientifically to help cure disease. [...]

What is the best way to enter truth? To encounter suffering (*prasop khwām tuk*). Healthcare workers have a great opportunity to encounter suffering every day.

This document is a manifesto for the reform of medicine, beyond the modern, into the heart of humanity (*khwām pen manut*), based on a royal command.

“The King Father” refers to Prince Father Mahidol Adulyadej, the father of King Bhumibol Adulyadej (Rama IX). He is often considered the father of modern medicine in Thailand. Legendarily, after seeing the abhorrent condition of Siriraj Hospital in Bangkok, Prince Mahidol left his military career to study public health and then medicine at Harvard, and returned equipped with funds from the Rockefeller Foundation to launch the modernization of medicine in Thailand. As one doctor told me in a crowded hall between patient visits, “the father of medicine was also the father of our King. That means that medicine and royalty are cousins.”

Prince Mahidol’s famous call to medical students is “I also want you to be human (*manut*).” The word *manut* is difficult to translate, and “human” is a complicated choice. In English, “human” has contradictory undertones. If one “appeals to a common humanity,” “human” is infused with ethical goodness that transcends the animal existence of man. But other uses, like: “Oh, well, you are only human!” imply the flaws inherent in being the creatures that we are. In all, “human” stands in for a slightly optimistic profile of *what we are* as creatures, our condition as moral beings.

*Manūt* is slightly different. In daily speech, it is often used interchangeably with *khon* – person.<sup>32</sup> But in philosophy and religion, *manūt* is *opposed* to *khon*, and is used precisely to differentiate ordinary people from those individuals who have engaged in enough introspective spiritual practice to encounter and embrace wisdom. In Buddhism, humans have a telos – a potential state of perfection, and thus an ultimate goal of living – in the form of the enlightened being (*uttarimanutsatam*) – which translates literally as “an ultimately *thamma*-aligned human (*manut*)” – a human (*manut*) who has become so one with the wisdom of Buddhist teaching (*thamma*) to be freed from the cycle of suffering. *Manut*, then, is a person (*khon*) walking the path to humans’ telos, interested in gaining the wisdom that will take him there. Prince Mahidol was not saying “I want you to be ordinary people,” but “I want you to be wise and on your path to enlightenment.”

Already, out of this basic explanation of humanity, a kind of ethical figure begins to emerge. Unlike the figure for Kiang, this figure is for Ampha, for a kind of healer. Humanized health care proposes to reform medicine by creating an idealized image of the health care worker who pursues wisdom through the practice of medicine.

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<sup>32</sup> Several people I interviewed said they felt this daily usage of *manut* was actually a slippage into Thai language from the English use of the word, and that the more “authentic” meaning was the way that *manut* appears in religious texts.

Wisdom is further detailed as consisting of truth (*khwām jing*), goodness (*khwām dī*) and beauty (*khwām ngām*). This definition is a conspicuous echo of Buddhadasa’s definition of human (*manut*), around which he organized much of his teachings. Truth is nature (*thamma*), the way things are. Goodness (*khwām dī*) is the quest to understand and experience nature (*thamma*) through correct morality (*sīn*), concentration (*samāti*) and wisdom (*panyā*). Beauty (*khwām ngam*) is a life lived in accordance with this goodness through correct action (*kāyakam*), speech (*wajīkam*) and thought (*manōkam*) (Buddhadasa 1956, Buddhadasa and Santikaro 1994). Humanized health care contains a complete ethical framework, the center of which is *manut*, the human, whose purpose is primarily to face and understand the truth. The components of this ethical framework – morality, concentration, wisdom, right action, speech and thought – are built upon the concept of truth, and an imperative to face it.

The reward for practicing this kind of medicine, according to the manifesto on humanized health care, is “abundant happiness.” Or in the words of Nurse Ampha, it is finding “true value” in one’s occupation. Without this quest to be human, health workers are “all stressed, work is hard, and they cannot take it. Everyone is afraid of being sued. If they can enter into the heart of humanity, they can reduce and eliminate their stress and be truly happy.” Doctors and nurses do not make enough money; the work is stressful and long. No one wants to be health care workers anymore. The health care labor market is failing and increasingly privatizing, drawing workers out of the impoverished public health system into jobs that reward their difficult labor (Komatra 2005, Suriya, Srivanichakorn, and Jirojanakul 2005). Without money, the public health system must find a non-monetary reward. For humanized health care, that reward is the “abundant

happiness” that results from facing the truth. The result is a currency in a market of value. Healthcare workers may not find monetary value in their work, but they find spiritual value.

### **End-of-Life Care**

In the 1980s, a new international medical field known as “palliative care” emerged in Western countries – a modified version of hospice, emphasizing hospital-based and doctor-dominated expertise in care of the dying. This movement was driven largely by the AIDS epidemic and a need for expertise to deal with the medical, spiritual and administrative consequences of a dramatic increase in the death of young patients in hospitals. The discipline quickly expanded beyond AIDS into general realms of death and dying in hospital medicine.

The field arrived in Thailand in 1992 in the hands of Temsak Phungrassami, a radiation-oncologist from Songkhla who attended a certificate course in Palliative Care in Australia and returned to teach the discipline in Thailand. He began with translating his Australian mentor’s handbook on Palliative Care (Maddocks 1992) into Thai. After Buddhadasa’s death in 1993, Temsak began to include Dr. Prawet’s book about the teacher’s death in his courses. Over the following ten years, the discipline took off dramatically in Thailand.<sup>33</sup> Those hoping to design palliative care programs looked to Temsak as the source of wisdom and practical experience. Buddhadasa’s death, and the social issues surrounding it, became central in the teaching agenda of the evolving discipline.

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<sup>33</sup> For an alternative history of palliative care in Thailand, see (IOELC 2009). The history of palliative care that appears here is from my own primary research.

In the mid 1990's, a set of philosophically-minded doctors at the Ministry of Public Health started a network of people interested in caring for patients at the end of life. The group's founder, Dr. Chusek, was from the Department of Traditional Medicine and worked mostly on the philosophies contained in different medical systems. He was interested in the end-of-life as a site of philosophical quandary in both modern and traditional medicine. They gave the organization a poetic title: *chīwantārak*, a fusion of three Sanskrit words: *chīwa* – meaning living, conscious beings; *ārak* – meaning to guard or caretake; and *anta*, meaning a last moment or ending. The group quickly took on an eclectic membership united primarily by their quest to understand the philosophical and spiritual underpinnings of medicine and health, with the end-of-life as their focus. The organization drew naturopathic healers, qi gong practitioners, temple abbots interested in caring for dying patients, and volunteers seeking to use end of life care to perfect spiritual practice.

The motivation for those involved in the network was similar for all – from doctors, nurses and alternative medicine practitioners to monks and individual meditators. “Why did you get involved in this field?” I asked Sakon Singha, President of *chiwantarak* beginning in 2006.

“Originally I trained as a surgeon,” he explained. “But I was not happy. I was just putting people back together, like a mechanic. I thought that maybe I wanted to be a scientist, so I went to study a PhD in transplant immunology in the UK. But I was still not happy. When I returned from England, I saw Dr. Temsak, who had started working in end of life care. He was so happy. And I thought to myself, ‘I want what he has.’ I

dropped everything and started studying end of life care with Temsak. Since then, I have been happy. I am lucky to spend every day thinking about the truths of nature.”

On the healer’s side, then, the motivation to become an expert on end of life care is personal spiritual transformation, a series of practices of the self that produce happiness in vocation.

Two ethical figures emerge from these movements, from Putigā and Humanized Health Care and the new medical discipline of end of life care. One is the patient who faces reality, and by so doing understands the nature of existence. The other is the healthcare provider who encounters suffering as an opportunity to acquire wisdom. These two ethical figures push on one another. They co-create one another. As nurses and doctors embrace the ethical figure of the healer with true value, they begin to push patients to know about their deaths, to bring medical realities into the open so that their spiritual correlates become available for discussion. As patients embrace the ethical figure of the patient who seeks wisdom through experience, they begin to push on their doctors and nurses to become the kind of practitioners who can discuss death openly and with spiritual wisdom. The dialectic interaction between these two new and idealized ways of being creates a healer-patient relationship that is full of persuasion and motion.

### **A Knot in the Heart**

This motion can be seen in one of Putigā’s central conceptual technologies for facing death: the “knot,” or *pom*. In general Thai, *Pom* can be used to refer to a literal knot, but it appears more often in idioms for social or psychological complexity. *Pom panhā*, literally “knot-problem,” means the heart of a situation, the part of something that

must be loosened or untied for a problem to be solved. In psychology, *pom* means a “psychological complex.” In Putigā’s lexicon, *pom* is imported as a specific technical term to describe something that prevents peaceful death, a knot of mental worries that ties up a person’s mind, preventing her from letting go and moving through death with an empty heart. The term was invented by Fong, a core faculty in Putigā and the senior nurse in Temsak’s department of radiation oncology in Songkhla. Fong developed the term over dozens of years caring for terminal patients to describe the obstacles she observed in people’s lives and minds that prevent them from letting go of life peacefully.

“I started using this word maybe twenty years ago,” Fong explains to those who come to learn about death from her. “I almost died myself. I didn’t want to die because I was worried (*hūang*), I still had something [in my heart]. I was unconscious, but I could hear everything. And so I made a contract with the Messenger of Death (*yomatūt*) that I would return and understand what was in my heart. And so I started working with dying patients.” She made a commitment with Death to come back and understand *pom*, the obstacle that sits in one’s heart at the edge of death and blocks peace.

Asking Fong to define *pom* leads nowhere. She is a brilliant organic intellectual, and the concept of *pom* has been built out of so many people’s stories that by now she thinks only in stories. The word itself is an accumulation of a thousand intimate moments trying to push through the wall at the edge of patients’ deaths. Each time someone asks for a definition of *pom*, she reveals one of these moments. “She never forgets anyone,” a Putigā conference leader told me, “she thinks with stories, and she

never tells the same one twice. She must have thousands...” I recorded dozens of these thousands of stories.<sup>34</sup> Here is one:

One patient I remember fell from a truck while at work and lost 97% of his brain function. The patient cried when I said the right thing... I figured out his *pom* and went straight to the right point, and he cried tears even though he was unconscious. But before I could talk about his *pom*, I had to find out what it was from his relatives. I asked his wife what he was like before he was unconscious. One day, before the accident, he had said to his relatives that he wanted to make merit (*tam bñn*) by making an offering to monks (*sangkhathñn*), and that he missed his son, who was paralyzed.

I was called to a palliative care consult because his wife wanted to remove the endotracheal tube [respiratory life-support]. But we could not remove the tube, because it is unethical. So I went to the patient’s room to ask his wife why she wanted to remove the tube. I asked the wife, and she said that she could not care for her husband because she had to take care of the paralyzed son as well. She wanted to sacrifice her husband’s life for her son’s.

I didn’t think that he could live much longer, because of the brain damage. So I told the wife: “you must be prepared, your husband may die soon.”

I told her to make an offering to monks (*sangkhathñn*) in her husband’s stead. When she was done, I told her to go to her husband and tell him that she did this and that he need not worry about it anymore. And I told her to tell the husband that he does not need to worry about his son anymore because she is taking good care of him. And then we arranged for her to bring the paralyzed son to the hospital to tell his father in person that he is okay, to say “I am healthy and strong. You don’t have to worry.” All of these things were to untie the patient’s *pom*. And when all of this was done, the patient cried, even though he was unconscious.

[...] I told the patient that he had nothing left to worry about, so he should think about the yellow edge of the monk’s robes, to hold on tight to the robe. [The monk will lead him to heaven]. I told him: “if your physical body (*sangkhñn* – ‘conditioned thing’) can’t hold on, just let it go, and your mind will follow it.” [...] And the patient cried again, and died in peace very quickly. We were surprised because a few days earlier he was completely unconscious and would not react to anything. And now, he cried tears in response to what I said, and died peacefully.

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<sup>34</sup> I first interviewed Fong in the summer of 2005, and then again later during join fieldwork with Felicity Aulino. The material here comes from the 2005 interviews.

*Pom* is the knot of worries and fears that ties a person to this life, that causes the mind to hold on. It resides within a person's consciousness and radiates outward into their attachments in the external world. It is a mystery, both seen from the outside and from the inside, and it must be investigated, understood and then released.

Fong's stories all involve similar elements. Patients shed tears once their *pom* is uncovered and untied. There is often a performance by those who love the dying patient, a performance that goes "straight to the right point" to release the knot. The *pom* is specific more than it is general – it is about the particulars of a person's mind and situation. The *pom* is like a tense muscle, wrapped around the mind of the dying patient. One must simply find the right trigger point, press it, and then watch a wave of relaxation open into the patient's mind.

Fong has built the concept of *pom* out of years of experience with patients, and in her hands it is subtle and complex. There are also many remnants in it of the conception of death as a moment, of the predominance of crafting the contents of the mind at the moment when consciousness separates from the body. Putigā, however, imports the concept toward its specific end – training people to face the truth of human existence at the end of life. Putigā expands on the knot (*pom*) with the concept of facing (*pachōen*), stretching the moment of death out until it includes an experience that can be faced. In so doing, Putigā builds a series of technologies to train people to become the kind of religious individuals it hopes to see in society. The technologies are designed to transform death into an experience that can be faced in a practical engagement, both by the patient, who can use the experience to attain wisdom, and by the practitioner who can find meaning in the caring for the soul and not for the body.

## Confessional Technology

On the first day of Putigā's training, I am still disoriented. My Thai is inadequate. Standing in the hall before the afternoon's activities, I ask a participant to tell me what is happening next. She is a nurse from an intensive care unit outside of Bangkok. "Thai people are not used to sharing about themselves with strangers," she says. "This is a big problem. How can we care for people at the end of life if we're afraid to ask about intimate things? How can we know what to ask if we don't know how to share ourselves? We need to learn to break this habit in Thai culture. The next exercise is about this, about listening and telling."

One way to release a *pom* is to talk about it. If we tell our story to others, we cannot trick ourselves into hiding from aspects of reality. Thus, Putigā employs a series of confessional technologies. Thai culture is presented as a problem, as closed and needing opening.

In the conference room, we break up into pairs, and engage in "deep listening," staring into our partner's eyes for long uninterrupted minutes, and then listening to them tell a story without breaking eye contact. Following this we sit in a larger sharing circle to tell stories about mistakes and sorrows from our past.

As I sit down in the circle, I think of the myth that foreigners learn about Thai culture – that they should not expect ever to get close enough to someone to hear their emotions. And I think that I have never seen anyone cry in public in Thailand. I have sat in open patient wards and watched families swallow unbearable tragedy and keep face for the people around them. But in our sharing circle, as people begin to tell their stories, the sorrow becomes thicker and thicker in the room. A woman in her thirties tells about her

alienation from a schizophrenic father. A politician tells about relentless pressure from her parents to succeed, with the stress of their judgment weighing on her every hour and every failure. A doctor tells about losing his little brother to cancer, about holding him by the shoulders in his hospital bed as he died. At points, there is uncontrollable crying.

At the end of our sharing, Phra Paisal summarizes the process we have just been through:

When we talk about our selves (*tua ton*), it is difficult because we slam up against the reality of the self that we are in this moment and the selves that we have been before. Often our suffering is not from fighting with others, but because we fight with ourselves, because we cannot accept an aspect of who we are or used to be. We have all made mistakes and suffered losses in the past. If we look deeply at our mistakes, we will see that they are not our self in the present moment, they are part of past selves. We misunderstand them to be part of us. Talking about ourselves shows us this aspect of reality, and if we can accept this reality as it is, we can reconcile (*khēun dī*) or make a truce with (*sangop seuk*) or befriend (*pen mit*) our former selves. This will increase our happiness, our steadiness and harmony in life.

When we arrive at the end of life, if our present self can get along with our past selves, it will help heal us, help sustain us until we pass the end of life moment. But if we can't get along with our past selves, they may return to demand payment for moral debts (*thuan būn khūn*) or haunt us (*lāwk lāwn*) and avenge us (*kāe khāen*) in our last moments. This is a terrifying idea. We need to befriend our selves, before we get to the last moment, or it will come and do us violence (*ruk rān*) us in our weakest moments, especially at the moment when our breath stops. We must have the bravery to open and look deeply into our selves, to accept (*yāwm rap*) and face (*pachōen*) this truth.

As Phra Paisal explains, the moment of death, though important, is not enough.

There is work to do in the period of life that precedes death, in the content of the fears and challenges to character that arise during the process of dying. During this period, we must have the bravery to face the truth and investigate it as material for understanding nature and acquiring wisdom.

## Imagination as Partial Experience

But confession as a tool for revealing the disconnections between our past and present selves does little to prepare us for the actual experience of our end of life. How can we prepare in advance for an experience we have never had? The old concepts of death at work in Thai Buddhism are not geared toward this. Death as a concept is used only to shock us into spiritual practice or to show us the illusions of lust. Putigā does use some of the traditional practices of mindfulness of death. For example, Phra Paisal leads a death meditation and a visit to the autopsy room at a hospital to watch a pathologist crack open the chest and skull of a freshly dead heart-attack patient, as though we are monks engaged in an *asubha* meditation on the foulness of the human body to release our attachment to permanence and ego. But Putigā's main goal is to reach beyond these treatments of death as an idea to the experience of the end of life. To do so, the organization uses imagination, enactment, and encounters – tools designed to face the end-of-life rather than death.

On the second day of the training, we gather into groups of three for a role-play. My two scene-mates are a young pharmacist man with tightly cropped hair and preened clothes, and a middle-aged woman doctor with dark curly hair. In our sharing session, I had already learned about each of their lives. The pharmacist told the story of his sister who died from cancer eight years ago. The doctor told the story of her own battle with cancer ten years before, still in remission now, but with some lasting side effects like back pain. We reach into a bag and withdraw our roles in the play. My role reads:

HUSBAND. Your wife has end-stage cancer. Yesterday, her condition worsened so much that you had to bring her to the hospital. The doctor tells you that your wife's bile duct has become obstructed from the cancer. She will need surgery, or she will not live longer than seven days. The surgery will not cure her cancer, but might make her live

longer. But it could also have complications. You know that your wife would rather spend her last days at home with your two children (both younger than ten) than risk dying in the hospital. You want her to live as long as possible, but you understand her wishes and will support her in refusing treatment.

I ask the others what their roles are. The doctor has been assigned to play the patient with cancer and obstructed bile duct, and the pharmacist is meant to play her brother. They look at each other and at me with big, heavy eyes. The similarity to their real lives is uncanny. The young man lost his sister to cancer, and now he will play the brother of another imaginary dying patient, sitting over her as she lies on the conference room floor, just as he sat aside his dying sister's bedside. And the middle aged woman, as she lies down, is lying into her own deathbed, where she can remember standing at the precipice of losing herself.

“Is this okay?” I ask them. “Can you do it?”

The young man smiles sorrowfully at me, already tearing up. “It is good. We need to face reality. The closer this is to the real thing, the better.”

The dying woman's brother has come to the hospital to convince her to accept treatment. Sinking into the role, sinking into his past, the young pharmacist argues with the middle-aged doctor. “Don't you remember,” he says, “how we used to play in the fields? And how our parents did everything to be with us? Don't you want more time, just a little more time with me, with your children?” And the material, of course, is from his own life, and he remembers wanting to yell at his sister, to make her live longer. The knot that was in his heart then, and still sits in his heart now, has come out into the room. And the doctor, who in real life lived through her cancer, lies on the floor remembering what it was like at one time to think she was dying.

In the exercise, we have imagined ourselves in the period of life before death, in the “end of life.” We do not imagine the moment of death or the process of dying, but the emotions and experiences of the period before death, when we need to negotiate our relationships, our fears and attachments, our many selves that must be reconciled to one another. Through this exercise, we have begun to craft a new interval of time in our vivid imaginary. We have begun to craft the end of life, and to teach ourselves to be interested and engaged with it as a zone of spiritual learning.

### **Finding Reality to Face**

Thot and I walk through the crowded halls of Nakhawn Pathom’s Provincial Hospital, the central public hospital for a province neighboring Bangkok. We have come here on a field trip from the “Confronting Your Death Peacefully” training center to practice our new-found skills on real patients. Thot is walking slower and talking faster than usual, and from this, I know that he is nervous. He has also reverted to teaching me about Buddhadasa, a familiar and comforting topic for him. Thot is my roommate at Putigā’s training. I know from long evening chats that his goal here has little to do with learning to care for dying patients. His impoverished childhood was fraught with suffering and his family was full of mental illness. Thot threw himself into studies, became a dentist and devoted his life to making money. But the sorrows and insecurities from his childhood plagued him, and the more money he made, the less stable and happy he felt, until he finally turned to religious teachings to learn how to free himself from suffering. In his meditation practice, he discovered mostly fear, a fear of death and of

connecting with other people. He came to the Putigā training to learn to face and release his fear.

Now we are walking through the hospital, with its throngs of patients and families and its open-air gardens, and I can feel the fear mounting in Thot as he walks next to me. Since my Thai is still awkward, we have agreed that today I will just accompany and watch. This makes Thot feel more comfortable, because he is worried I will accidentally open a Pandora's Box, but it is also terrifying, because he needs to run the show.

The head nurse of the neurological ward greets us and tells us some sparse details about the patient we were going to visit: "She is 'hopeless,' with a degenerative neuromuscular disorder, but no one knows how long she has to live. Also, the patient does not know that she is dying, so don't talk about dying." After this description, the nurse tells us the room number and turns back to her work.

The patient's door is open. We look in on a short hall that leads to a hospital bed and a mat rolled out on the floor beside it. A middle-aged woman, with a girlish face and a pear-shaped body steps up expectantly from the floor to greet us. Thot steps in ahead of me, his nervousness exploding out of him, and begins speaking rapidly. He says various iterations of: "We are volunteers. We're here to give heart power (*hai kamlang jai*)."

The patient is connected to a respirator, but not through the mouth, through a tracheotomy. The middle-aged woman introduces herself as the patient's daughter, and says that her mother can understand things, but cannot talk because of the respirator. We sit and say hello to the patient, who is lying still, strapped into the machines of modern medicine. She smiles broadly back at us. Over our shoulder, the daughter tells us that they want to cure her mother's disease and go home. Thot, clearly flustered by the

patient's inability to talk, tentatively reaches in to touch the patient's hand. The daughter smiles at this and tells That that her mother is unable to feel her body below the neck.

At this piece of information, That's legs begin to shake. For two days, we have role-played about how to talk to patients and how to touch patients, and here is a woman who cannot talk and cannot feel. Nothing about what is happening fits the image in That's mind of how this interaction should go. Clearly, there is a knot (*pom*) in the room preventing the family from talking about death, but suddenly the way to unlocking it is opaque. That stands up quickly, fumbling: "I'm sorry, we have to leave. I am not good at talking, not good at talking. We are just here to give heart power (*hai gamlang jai*). Nothing more. Good luck, get well." And we shuffle out of the room.

Outside in the hall, That is visibly upset, perhaps even angry. "They did not prepare us enough to do that. We have not been trained to deal with situations like that. How are we supposed to find out the patient's *pom* in there? I just don't know what to do..."

But later, at dinner, his perspective has shifted. Thoughts about the experience overflow: "Being in the actual room, it was not about dying. It was about the family, and about talking. I didn't know what to say. I didn't know them and there was no time. I am not used to talking to people like that, about things that matter so much. How can I know what to say? I don't know how to just *be* in a place like that. This is so good for me."

This last phrase, "this is so good for me," strikes me. That's purpose for being at the training has little to do with learning to take care of dying patients, about walking into

a room of strangers and asking them intimate and dangerous things. How, then, is it good for him?

“There is something in me that keeps me from facing difficult things,” he explains. “I don’t want to talk about them with people. It is uncomfortable. If I can understand why, then I will understand myself.”

That has an image of himself, of the kind of person he wants to be. It is an ethical figure. He wants to be the kind of person who walks into difficult things, and uses the emotions that he finds there to understand the nature of his own mind. He wants to face the truth, and reveal that truth to others. When he arrives at his own end of life, he wants to encounter the difficulties there and study them. And now, while he is not yet dying, he wants to learn how to help others face the ends of their own lives, as a way to find value in interacting with others.

### **An Assembling Pair of Ethical Figures**

In July, 2007, the movements around the end of life coalesced into a conference in Bangkok with over five hundred participants, entitled “Culture, Death and the End of Life” (Komatra 2007). Dr. Prawet gave a talk about Buddhadasa’s death, about the rifts in Thai society that it laid bare, and the kind of humanized medicine that it called for. Phra Paisal gave a talk about “death before death,” about experiencing the end of life as a tool for honing the mind. Few emotions were shared. The conference was not about grief, or about counseling. It was about the mind, and using the experience of the end of life as a tool for understanding it.

The centerpiece of the day was a documentary made by Temsak and Pi Fong about a cancer patient named Supaporn that they cared for at the end of life. Supaporn had been a meditator her whole life, and when her breast cancer came, she talked her doctors into not treating it. She decided that she wanted to use the experience to study suffering. The tumor became necrotic, opening her chest up into a giant black hole of putrid dead tissue. She removed the bandages frequently to study it. She studied the pain and the nausea. She did not want opiate medications, until the end when the pain became so intense that it overwhelmed her ability to focus on it. She had to talk her doctors at various points into the merits of her approach. They were so used to fighting disease that they felt powerless in the face of letting it be.

When I asked Temsak about the documentary, he said: “We wanted to create a legend (*nitān*).”

“A legend?” I asked. “What do you mean?”

“An ideal (*tua pāep*) of the way that someone’s end of life could be. We hope that the legend will spread so that people know what is possible. Supaporn taught us how to take care of her soul (*jit winyān*). She taught us that it was more important than her body.”

At the conference, the streams of thought that had been developing since Buddhadasa’s death – humanized health care, Putigā’s religious reform, and the new discipline of end-of-life care – had coalesced into an assemblage with a single statement of purpose: a “legend,” a new ideal, a pair of co-creating ethical figures: patient as seeker of wisdom and provider as caretaker of the soul.

This pair of figures is what accompanied Nurse Ampha as she stood outside Kiang's room, wishing she could talk with Kiang about dying. Like the sign on Kiang's wall, persuading Kiang gently to be a rights-wielding citizen, Ampha's hope from the hall manifested in gentle persuasion for Kiang to become a seeker of wisdom. Ampha brought up the issue in patient rooms, talked quietly about it at the nursing station. And when it came time to discuss with patients, it would be impossible to remove this kernel of hope from her mind. She was a gentle tug on the frameworks that dominated Kiang's ethical world.

The figures of patient as seeker of wisdom and as rights-wielding citizen are related, but not identical. Ampha and her teachers are not interested Kiang's political empowerment relative to those around her. They are not interested in her pushing back on her doctor to wield her rights. They are not really even interested in medical decisions. They are interested in *experience*. They want Kiang to become a knowing subject, not because knowledge is a right, but because it is an opportunity. Attaining wisdom takes time, and it takes walking into truth, into the heart of suffering. Ampha and her team want Kiang to elongate the period of dying, to consciously delineate it and stretch it out to maximize the time for study, for experiential wisdom. This is a goal different from the sign on Kiang's wall. In fact, advocates for the figure of patient as seeker of wisdom define themselves in opposition to patient-rights advocates. Knowledge is an opportunity, they might claim, not a right. Its purpose is not to entrench people in their individuality, to create camps and opposition and sides of a conflict. Its purpose is to make everyone involved face the truth of nature, to experience and attain liberation from suffering.

Thus the two new figures, the idea of patient as seeker of wisdom and as rights-wielding citizen, arrive in the ethical world of Kiang's hospital room, with its already tense frameworks of giving life and dying at home. These frameworks are all available in the contemporary moment, hovering and waiting to be used by individuals to navigate the process of dying, or of the end of life. Because of them, Kiang's room has become a heterogeneous and confused ethical landscape, where frameworks sometimes harmonize and sometimes conflict, but always require negotiation. How does this process work? How do individuals, families and practitioners find their way through this confused ethical world?

## **Chapter Six:**

### **Conclusion: Ethical Worlds**

#### **Disjunctures**

Standing outside Grandfather Nanban's hospital room, where he lay dying of lung cancer, I was told by a nurse to "be careful, because he doesn't know what disease he has or how bad it is." Then, in the patient's room, Nanban's daughter Buaphan told me that they did not want to participate in my research; she was worried I might let her father know too much about his disease. On the wall, the same sign that appeared in Kiang's room announced Grandfather Nanban's right and responsibility to know his diagnosis. But nurse and daughter were actively colluding to prevent this from happening. I was a risk, an unknown cultural agent, who might not understand the precarious play being enacted and thus disrupt the illusion.

But when I arrived three days later, the illusion had collapsed on its own. The nurse explained, "the doctor accidentally told the patient he has cancer, and now Mr. Nanban has run out of heart power, and he is worsening fast. The family needs you to help give him heart power."

Grandfather Nanban's daughter later explained this as a form of killing. "The doctor killed my father," she said, "by telling him what he had. My father ran out of heart power. The words the doctor used made my father think too much, and so he died. Too fast! There wasn't even any time to say goodbye." Knowledge made Nanban's heart power drain from him, as though his animating spirit (*khwan*) had fled his body.

A bit later, I asked Nanban's daughter Buaphan, "What did the doctor say after telling him?"

“He said: ‘a patient has a right to know his disease.’”

“What do you think of that?” I asked. “Did your father have a right to know?”

“A right to think too much and die fast, what kind of right is that?” she said, a bit agitated, and then appeared embarrassed. It was clear that she was judgmental of the doctor, and thought that he was using the phrase “patients have a right to know” to defend his actions. The doctor, Dr. Danai, was using patient rights to defend his own mistake. When he said “a patient has a right to know his disease,” he really meant, “a doctor has a right to tell.”

The figure of patient as rights-wielding citizen was clearly present in Nanban’s hospital room, but in the messy negotiated reality of the situation, something had happened to it. It had mutated. It was used to justify a doctor’s mistake, to empower a doctor relative to patient and family, not the other way around.

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At another time in caring for Nanban, a second ethical figure emerged in his hospital room, the figure of patient as seeker of wisdom. Nanban was still alive and in the hospital, and I sat by his bed and talked with his son Sak about what was going on. I looked over at the bedside table, stacked with books of Buddhist teachings about death.

Sak explained, “Grandfather was a great Buddhist practitioner. He studied his whole life and he was a monk at Lūang Pū Sim’s monastery. [...] Father has read and understood these books. [Life is] birth, old age, pain and death. Father understands this. But then he encounters this – himself, his own real life – and his heart sinks (*jaihāi*), and he is full of regret (*siadāi*) and worry (*kangwon*). These books are only principles (*lakthān*). Reality is very different.”

The figure of patient as seeker of wisdom was hovering in Nanban's room, but he was out of alignment with it. Sak could feel the presence of the figure, and he explained Nanban's failure to match it, his voice full of knowing regret.

Knowing his diagnosis, Grandfather Nanban decided that he wanted to go home. It was no longer an option for his children to leap to his side, like Jae leapt to Kiang's side, and say: "We will beat it! You have to fight, be strong. Keep your heart power up! Don't let go!" For Nanban's family, the process of paying back their debt of life was not over. But it was over for Nanban himself; the end of his life had arrived and he wanted to go home, and since knowledge had been shared, there were no arguments left that his family could use to keep him at the hospital.

The nursing staff arranged for Nanban to be transferred first to the local community hospital, and then home with an oxygen tank and a prescription for slow-release morphine for his pain. But the morphine prescription had to be filled back at the provincial hospital, three hours drive away. And more than that, his family did not want to fill it, because they felt that morphine could hasten death and thus should only be used in the "last interval of life" when the process of giving life was already over.

I arrived to visit Grandfather Nanban in his mountain village, his small house nestled at the base of a limestone cliff, severe in the cold of winter. Nanban was lain out on a bed in the corner of the living room, writhing and moaning in pain and discomfort, cared for by a constant rotating vigil by his many children. I sat at his bedside with his son and daughter, Buaphan and Sak, as they spoon fed Nanban his pills crushed into a paste. I pulled Buaphan aside and asked about morphine, and she said, "If we give him morphine, he will fall asleep and never wake up. We need time to make merit for him at

the temple. We need to talk to him again. Just one more time. The doctor told him [his diagnosis] and then he was shocked and became terrible so fast. We haven't had a chance to talk to him."

I heard Nanban moan and thrash in the background and my heart broke both for his pain and for Buaphan's pain standing in front of me, desperately trying to have another conversation with her father. I shared my opinion that sometimes pain treatment can help people calm down and stop fighting so hard with the suffering, and they can wake up and be more lucid as a result. She smiled kindly and thanked me for the advice, but I saw in her eyes that it wouldn't matter.

We returned to Nanban's side to overhear his son Sak saying to him, "Father, we have made some merit for you at the temple."

"Want to ordain," whispered the old man in gasps, "want to ordain."

I looked at Sak for an explanation, and he tentatively said, "When he was young, he was a monk up on the mountain. He is remembering that time."

But later, I asked Buaphan again about the comment, and she said, "I don't know, maybe he thinks that the merit from ordaining would help with his pain, or with his rebirth. He is suffering a lot, and thinks if his mind were more ready, he would not be suffering so much."

Again, the figure of patient as seeker of wisdom is hovering in Nanban's room, and he is not aligned with it. He thinks he has failed to be the right kind of dying individual, one who has not used the last interval of life to prepare for the moment of death, to attain wisdom and be free from suffering.

Like Kiang's hospital room, Grandfather Nanban's deathbed is an ethical world – inhabited by an imperative to give life, a drive to die at home, the ethical figures of the patient as rights-wielding citizen and as seeker of wisdom. But in Nanban's case, driven by the speed of his illness and by a series of haphazard misfires of communication, none of these ethical frameworks are functioning well. And more importantly, in the context of Nanban's complex ethical world, each framework has become mutated and disjointed by the presence of the others.

In the hospital, Nanban's room was inhabited by the figure of Nanban as a rights-wielding citizen. The sign on the wall wanted Nanban to know his diagnosis. But this sign's wishes were not enacted because telling Nanban his diagnosis would destroy his family's process of giving life. Nanban, despite a lifetime of spiritual practice, did not have the level of mind required to know the truth, and so he would lose heart power and die quickly. Everyone understood this negotiated relationship between the two ethical frameworks. Patients have a right to know their diagnosis, but that rule can be ignored if the truth would kill. Dr. Danai did not intend to tell Nanban about his disease.

But then there was an accident, a mistake in communication. Dr. Danai, probably exhausted from caring for too many patients with too little time, spoke too loudly, and Nanban overheard. And then Nanban asked Dr. Danai a direct question. Dr. Danai could certainly have lied, a slightly more extreme version of what other doctors do when they say, "don't worry, you will get better!" But suddenly the lie would have been too bold, would have come too strongly up against the new hovering framework of patient as rights-wielding citizen. And so Dr. Danai told the truth.

The nurses explained this not as a decision, but as a mistake, taking place at the moment of whispering too loudly in the room. After Nanban overheard, the damage was already done. The lie would have been too large a stretch. The truth was out.

Later, when Buaphan confronted Dr. Danai, he drew the figure of Nanban as rights-wielding citizen out of the set of concepts inhabiting Nanban's room and used the concept to justify his actions. He essentially pointed to the sign on the wall and said "I have not committed wrong action, because there is a framework here that supports that action." The effect of the justification, however, was the opposite of the ethical framework's historical purpose. Rather than empowering Nanban to be a rights-wielding citizen, the ethical figure was used to acquit the doctor of a mistake – a mistake that Buaphan would eventually describe as fatal.

Alongside patient rights, the figure of patient as seeker of wisdom also inhabited Nanban's room, especially on the mountain. Knowing his diagnosis, and unable to run from it, Nanban began the process of facing the actual lived experience of the end of his life. He knew that the contents of this experience were religious, that the illness might be a karmic messenger (*jao kam nāi wāen*) come to exact a toll. But Nanban was failing to become the ethical figure that lurked in his room. Facing the experience was not producing wisdom in the face of suffering, it was only producing suffering. There simply wasn't enough time to study the pain, to learn from the truths of nature that awaited him in the experience of the end of life.

Sitting in Nanban's room on the mountain, watching him suffer in pain, I thought back to one particularly chaotic day in the hospital, in a crowded and open internal medicine ward. Of forty patients in the ward, a dozen were crashing, and the doctor on

duty was losing the race to figure out what was wrong with each of them. The doctor was Dr. Danai, the same physician who had accidentally told Nanban his diagnosis. Dr. Danai had a sweet smile and a clear devotion to public health medicine. He spent longer at the hospital than many other physicians who rushed off to private clinics in the afternoons and evenings.

On this day, I watched Dr. Danai rushing between patients. One older man was crashing from multiple organ failure. He had not regained consciousness since arriving at the hospital and his blood pressure had dropped dangerously low several times. In one of these moments, Dr. Danai removed a book from his pocket, showed the cover to the patient and whispered a few words in the old man's ear. Then he put the book on the man's chest. I walked up to hold the patient's hand, and couldn't help looking at the book, which was by Lūang Pū Sim, the same famous monk whose books sat aside Mr. Nanban's hospital bed.

When Dr. Danai returned to the bed of the man I was holding, he looked embarrassed and put the book back in his pocket. When I asked what it was for, he said, "I thought a familiar face, a familiar teacher, might help prepare this man's mind. But it is not worth it. It is too late. It takes too long to prepare the mind." And he rushed off.

Dr. Danai valued the framework of giving life enough to try not to tell Nanban about his diagnosis, but when he messed up and told, he drew on the figure of Nanban as a rights-bearing citizen to justify his actions. Dr. Danai also valued the figure of the patient as seeker of wisdom enough to try in an emergency to prepare a crashing patient's mind for the moment of death. But, he explained, it takes too long to prepare the mind,

meaning that a patient can only seek wisdom if he has time to experience this new period of time, the end of life.

The same problem plagued Nanban in his living room, where he lay dying in the cold of mountain winter. Despite Nanban's long engagement with Buddhist meditation practice, and despite his knowledge of his disease, facing the truth was not helping. Being the seeker of wisdom requires a certain level of mind, requires being a certain kind of religious subject who has crafted a mind over a lifetime. But it also requires a certain kind of dying, one that takes long enough for a seeker of wisdom to study its contours. And it takes a death that presents some suffering, but not immense suffering, because who can study so much suffering?

The other frameworks at work in Nanban's room were also in conflict. The imperative to give life was still operating, but the release of knowledge about Nanban's diagnosis had disempowered his family in deciding to keep him at the hospital. And it had made Nanban's heart like a cracked jar. He had lost his heart power, and though his family poured more into him by doting on him and caring for him, he could not hold on to it. He was an empty vessel, leaking, dying so quickly because his body was pulled toward death by his mind.

In the reality of a difficult situation, all of the ethical frameworks in Nanban's ethical world had come into conflict. Some of them had become mutated, used for purposes different from their original ideal. Although Nanban's room was full of concepts about how to approach dying, those concepts clashed and slid against one another so that Nanban's ethical world was full of disjunctions, misalignments between available ways of making sense of what was going on, for making and justifying

decisions. Individuals navigated Nanban's end of life by reaching haphazardly and awkwardly for ethical frameworks, trying to maintain an ethical identity, trying to do the right thing. And the ethical world constructed in those messy moments was a world full of disjuncture.

### **Harmony**

When I first met Mali, the idea of her was introduced to me by Nurse Ampha. "You have to meet Mother (*māe*) Mali," she said to me, her eyes twinkling, "she is our first real 'end-of-life.'"

"What do you mean by 'end-of-life?'" I asked.

"Mali," she said, "knows what disease she has and wants to face it peacefully with meditation."

What Nurse Ampha meant by Mali being a "real end-of-life" was that Mali matched the ethical figure encapsulated in the new object in Thailand, the end of life. More precisely, Nurse Ampha thought that Mali was the perfect seeker of wisdom and rights-bearing citizen. Mali had known her diagnosis from the very beginning. She wanted to know. And the doctor could see in Mali's eyes that she meant it, and so she told her the truth. And with that knowledge, over the following year, Mali studied the nature of existence, and attained a great peace. Eventually, a month before her death, she said to me, "This disease has been the greatest gift to me. I am happier and calmer now than I have ever been in my life."

The other ethical frameworks that might have conflicted with this ethical figure remained in the room: paying back a debt of life and dying at home. Mali had a daughter,

a fifteen-year-old only child, who clearly had immense ties of affection and duty (*phūkphān*) with her mother. “She is still a teenager,” Mali often said to me, “she is still working out who she is. She needs me. She doesn’t want me to die.”

“What do you tell her?” I asked in return.

“What I need most now is to study this disease, to meditate and keep with my mindfulness (*sati*) and concentration (*samāti*). My daughter has meditated, and she understands, but still sometimes she needs me, and mostly she needs to give me heart power and feel like she is taking care of me, so last week I went home to be with her for a few days. The pain came back and gnawed at me, because I lost my mindfulness in the chaos of home. Over time, she understands more and more, and I can go more and more into mindfulness. She sees that it works for me.”

Mali’s daughter still felt the imperative to give her mother heart power to pay back her debt of life. At first, she wanted to be aggressive with surgery and chemotherapy, but Mali argued that chemotherapy drugs would alter her consciousness and prevent her process of confronting the truth. Mali slowly led her daughter to understand that the greatest gift would be peace and quiet, so that Mali could generate her own heart power. There was nothing in this that contradicted the imperative to give life. Mali never said to her daughter, “I am ready to die, let’s give up the quest for cure.” Instead she said that the most important way for her to cure her illness was to keep up her heart power, and the best way to do this was to maintain mindfulness. Instead of dispensing with her daughter’s need to give her life, she satisfied it by appealing to the theory of mind that allows heart power to come from within.

The same was true for dying at home. Her family increasingly understood that she did not want to die at home because at home she would lose her focus on seeing the tumor for its true nature. “Some think that the spirit (*winyān*) needs to leave the body at home or in the temple, but the only important thing is to face reality (*pachōen khwāmjing*), to have a clear mind (*jitwāng*). Then there will be no suffering, no karma (*mot kam*) and the spirit will be reborn well.” Mali had honed in on the core of the ethical framework that required dying at home, which was the optimization of the separation of spirit from body. One needs to be at home so as not to cling to anything, to want for anything. If she could solve the problem of attachment to things of this world by meditating, she reasoned, she would not need to be at home.

Mali was not particularly engaged as a rights-wielding citizen, but she was not in opposition to it either. She gently used her right to know to obtain the knowledge necessary for facing the truth. Nor was she in opposition to the frameworks of giving life or dying at home. She made peace with those frameworks for those around her, so that a paramount way of being could come into focus: her quest to use the end of life to understand her mind.

Becoming this ethical figure – using the experience of the end of life to attain wisdom – allowed those around her to move into the ethical figure of caretakers who find meaning in their work. “Taking care of Mother Mali,” explained one nurse to me, “is better than working. Every time I go in to check her blood pressure or change her medications, I leave happier than I went in. Everything in the room is open; she knows everything about her disease, and she has prepared herself already, so we can talk about

the end of life without any fear, without any secrets. It is very rewarding. I often go sit with her just to talk with her, but she meditates so often, I don't want to bother her."

Because of my research, Mother Mali came to think of me as a disciple, and so I was exempted from worrying about bothering her meditation. With me, she could explain her meditation process, especially about pain. She saw in me a curious soul, a meditator, and a fellow grappler with pain. For ten years, I have had a pain syndrome and have used meditation to help with it, to reach for the Buddhist promise of pain without suffering. And so we found ourselves with a common vocabulary. We found ourselves able to face her "end of life" together as material for spiritual study. And by joining her in this process, I found myself moving into the ethical figure that is co-created alongside the figure of the patient as seeker of wisdom.

One day, I visited Mother Mali, and she was meditating as usual. We sat, and she explained the stages of meditation she had passed through before this illness, and the stages that the illness had helped reveal to her. In the middle of a sentence, she began to shake uncontrollably. "Cold," she said, "I am so cold." Every muscle was shaking, the strain was immense on her body, and she could not control it. Her back arched in strain against an invisible monster. The tumor had coughed a set of molecules into her blood that was causing chaotic body temperatures and erratic blood pressure. The nurse and I packed her body with hot water bags, and she improved for a moment, and then began to moan and shake again. I held her down with my shoulders, pushing the warm bags into her.

Her suffering began to break my heart. "Mother," I said, "this is something that morphine would help with. I think it might be a good time to have some morphine."

She shook her head. She had tried morphine at the beginning of her hospitalization, but it had broken her mindfulness and increased her suffering even though it had decreased her pain. “This is amazing,” she said. “My body is shaking, and I cannot control it. My mind and my breath are following my body, and I can’t get my body to follow my mind or my breath.”

“Please, mother,” I said, about the morphine.

“It’s okay,” she replied, “These episodes only last half an hour. It’s okay.” So I held her down. Eventually, the episode passed.

We sat in silence for some time, and then she said, “I have spent many hours meditating with mindfulness of my breath (*anapanāsati*). This is how the Buddha attained enlightenment. In the first stages of the meditation, you manipulate your breath and observe how the mind follows it. The same is true with the body in walking meditation. Moving the body makes the mind move. You learn how the breath, the body and the mind are really one body, and they follow one another. During that shaking, I could not get my body under control. My mind and breath followed my body. All three went together into suffering. It is a good lesson. That is something you can only know by experiencing it.”

Out of the experience of the end of life, Mother Mali found extraordinary wisdom. And being at her side infused my research with so much profound meaning that I began to feel the lure of the new set of co-creating ethical figures that were emerging in Thailand, the seeker of wisdom and the caretaker of the soul. The “legend” propagated by Temsak and Phra Paisal had gravity to it, and I could feel its pull in my little hospital in Northern Thailand.

Mali's room contained all of the same ethical frameworks that inhabited Nanban's ethical world. But unlike in Nanban's world, the frameworks had come into harmony rather than disjuncture. The imperative to give life was satisfied, as well as the imperative to die at home. And Mali was left to focus on understanding the process of dying and attaining wisdom through it.

One day, I was leaving the hospital with Tom Tem, who had come not to translate, but just to be with Mali. Tom Tem's goal in life is to practice an engaged Buddhism that helps her to understand human suffering and relieve it. As Mali reached the end of her life, Tom Tem and I wanted more and more to be around her, to the point that we began canceling other parts of our lives to come to the hospital. This time, as we were leaving, Tom Tem turned to me and said, "I think that Mali is approaching enlightenment. Something has happened, even over the past few weeks, that has changed her. She is really letting go of everything. At first, she talked about wanting to die at home, but now she says it doesn't matter because her mind is not clinging to anything, and you can see it in her eyes. She is just full of joy and nothing is in the way of it, not pain, not attachment, nothing. All of the rituals, the Thai culture, don't matter any more. After all of my spiritual practice, this is one of the first times I have ever seen someone like this. Right now, I don't want to do anything but be around her."

### **Negotiations**

Nanban's ethical world was full of disjunctures and mutations. Mali's ethical world was full of harmonies. Both engaged the ethical figures arriving in their rooms, the

standing frameworks of giving life and dying at home and the new frameworks arising out of the politics of death and social change in Thailand.

But most rooms are not extreme like Nanban's and Mali's. Instead, they involve an awkward but navigable truce between ethical frameworks. Kiang's room is the perfect example, where the frameworks are negotiated into a stable suspension, into a hierarchy.

Jae's response to her mother's 'right' appearing on the wall was, "A right to what? A right to know her disease, which can't do any good, can't be cured. A right to worry in her last days. That is not a right I want for my mother."

Nurse Ampha was upset by Jae's withholding of information from her mother, not because of an ideal of Kiang as rights-wielding citizen, but because of an ideal of Kiang as seeker of wisdom. "Mother Kiang," she explains, "will have no chance to prepare her mind for the final moment. How can she know she needs to meditate and chant if she doesn't know what is happening? This is not a real 'end-of-life' case."

But Ampha holds this ethical figure of Kiang only lightly. It is there, but only as a small tug of hope in Ampha's mind. And the sign on the wall holds the ethical figure of Kiang as rights-wielding citizen only lightly as well. With no one to enforce it, it sits peacefully inactive, a gentle pull on those who read the sign.

"Why don't you tell her what [disease] she has?" I ask Ampha.

"Her daughters are trying hard to do what is best," she says, "and they don't think their mother can handle the news. Telling Mother Kiang would disrupt the family and everyone's relationship and communication. They know their mother and her level of mind. I don't."

Kiang's room is not exactly full of disjunctures, but it is not harmonious either. It is negotiated. The figures of Kiang as wielder of rights and seeker of wisdom have been set aside. Ampha respects and understands Kiang's daughters' path to doing what is right in the face of a confusing set of options. Everyone agrees that only an intimate knowledge of Kiang's level of mind can be used to choose the correct path. Only her family knows her well enough to decide.

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I presented the cases of Nanban and Kiang to Drs. Wichai, Somsak and Vitoon when I interviewed them about patient rights in Thailand, and to Phra Paisal and Temsak and Sakol when I interviewed them about Putigā, humanized health care and end-of-life care. "Mr. Nanban's family," I explained, "felt like the doctor killed him by telling him. In other cases, nurses and doctors do not tell the patient anything unless the family allows it, because they feel that the family knows the patient best."

Despite their political differences, all six replied the same way. The following monologue encapsulates the themes well:

Patients must be told. They have a right to know, and they need to be able to make decisions about how to face the end of their life. But we need to work on telling patients in the right way. This is something that is new in Thailand, called the art of medicine. Truly, patients know anyway. No one tells them they are dying, but the patient can observe everyone around them. They can see that the situation is dire. They guess, but they don't dare to ask. When a doctor tells the patient too harshly, it is like a death sentence, it is like a blow from a weapon, and the patient runs out of heart power. But if the doctor takes time, gets to know the patient and the patient's level of mind, then the doctor can find a skillful way to tell. The doctor can present the information in a way that does not cause harm. The doctor is the person who should teach patients that it is okay to know, that knowing is good.

The ethical figures of patient as rights-wielding citizen and patient as seeker of wisdom propose a transformation on Thai society. But these new frameworks conflict with other frameworks already woven into real patients' ethical worlds. The most often solution to this conflict, as in Kiang's case, is a negotiated suspension of the new. But to those who are crafting the new ethical frameworks, that negotiated suspension must be eroded with time. Patients must be made to become the ethical figures arriving in their rooms. The solution, to activists, is a more skillful and subtle way of changing Thai society. Healthcare providers need to become masters of culture change. If Thais are to be enlightened or empowered via the end of life, then providers must be the ones that make them into new kinds of people.

Those proposing change to Thai society want to collapse the set of ethical frameworks in Kiang's hospital room. They want to remove the disjointed, confused experience of navigating multiple misaligned frameworks. In order to do so, they need to transform Thai society. They need to smooth out the edges of each of the frameworks so that they can align and meld. Doctors need to soften the way that they tell patients the truth, so that patients don't lose heart power. But patients also need to learn the value of truth, so that their store of heart power is no longer so fragile in the face of knowledge. The ultimate vision is the glory of a new period of time, the end of life, and embracing the experience of that period by everyone involved, without conflict or confusion. But to achieve this goal would require a broad program of social transformation, a social transformation precisely in line with the political agendas that produced the new ethical frameworks.

Because of a series of historical coincidences, because of Buddhadasa's death during an opening in politics and religion, a set of elements has begun to assemble around and craft a new object, the end of life. And this new end of life contains a set of ethical figures, of proposals for how to become an ideal Thai – how to become a rights-wielding citizen and a seeker of wisdom. This is how Kiang's hospital room has come to be the center point of agendas for the transformation of Thai society. And until this transformation is complete and settled, Kiang's ethical world, the experience of the end of life, will continue to be an unstable site, sometimes in disjunction, sometimes in harmony, always in negotiation. It will continue to be unsettled ground, a space inhabited by questions rather than answers, a site of ongoing change, with ripples out into all aspects of Thai society.

## Appendices

### Appendix I: Patient Selection Protocol<sup>35</sup>

| <u>Disease</u> <sup>36</sup>   | <u>Criteria/System</u>  |
|--------------------------------|---|
| OVERALL                        | < 60% one-year survival   |
| Cancer                         | Prognosis by specific type and stage of neoplasm → < 60% 1-year survival                        |
| Advanced chronic organ failure |   |
| Heart (CHF)                    | (1) EFFECT <sup>37</sup> “one-year” score >120; (2) Seattle <sup>38</sup> 1-year survival < 60% |
| Lung (COPD)                    | (1) FEV1 < 20% predicted; or (2) BODE <sup>39</sup> score > 8                                   |
| Kidney (ESRD)                  | (1) Candidate for dialysis or receiving dialysis; or (2) GFR < 20                               |
| Liver (ESLD)                   | (1) MELD <sup>40</sup> score >27; or (2) Child-Pugh <sup>41</sup> stage C                       |
| Stroke (CVA)                   | Bed-ridden and unable to self-care  |

<sup>35</sup> This selection protocol was used as a rough guideline for clinical selection to help explain to doctors and nurses the types of patients I planned to study. For actual selection, I relied heavily on the opinion of doctors and nurses at the hospital. Lab values required for the selection criteria were often unavailable, but provided a qualitative sense to physicians of the conditions I was interested in.

<sup>36</sup> Because of the unique cultural issues associated with the end of life in HIV/AIDS, I chose to exclude the disease from my study.

<sup>37</sup> For EFFECT rating system, see [www.ccort.ca/CHFriskmodel.aspx](http://www.ccort.ca/CHFriskmodel.aspx) and (Lee et al. 2003).

<sup>38</sup> Seattle score can be calculated online at [www.SeattleHeartFailureModel.org](http://www.SeattleHeartFailureModel.org). See (Levy et al. 2006, May et al. 2007, Mozaffarian et al. 2007).

<sup>39</sup> To calculate the BODE index, see (Celli et al. 2004).

<sup>40</sup> For MELD Survival, see [www.unos.org/resources/MeldPeldCalculator.asp?index=98](http://www.unos.org/resources/MeldPeldCalculator.asp?index=98) and (Kamath and Kim 2007).

<sup>41</sup> For Child-Pugh Score, see (Christensen 2004, Durand and Valla 2005).

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