

The Rhythms of Hospice Care

As we enter the hospice outpatient examination room, I notice it is devoid of medical machines. The doctor sits down before the computer, picks up the file lying on the desk, and reads through the patient's referral letter. I sit on a stool as far back in the room as I can. A corridor that runs along the rear of the room connects this examination room to others. By leaning back and peering to my left, I can see a nurse preparing to listen and take notes in the adjoining room. After the doctor finishes checking the patient's X-rays, he tells the nurse, "Please show them in."

The door slides open and the patient's wife and daughter enter the room. For some reason I expect the patient to enter as well, but his absence immediately makes sense; the patient, in his seventies, is bedridden with ureteral cancer. The doctor first confirms the wife and daughter's relationship with the patient and types this into the computer. He then pauses, makes eye contact, and introduces himself. He does not bother to introduce me, but when they glance in my direction, I give a slight nod. He asks the family to describe the patient's condition and the kind of pain he is experiencing. They explain how his urine has started to show blood and how his body often shakes. He has no bowel movements and his urine is being artificially drained from his kidneys. He is not coughing. He is receiving fluids intravenously. He is aware of his condition. The doctor types all of this into the computer.

The doctor then explains that their hospice has two kinds of rooms: one type is free of charge but on the small side, the other type is larger but comes at an additional price. The wife and daughter interrupt him: "Either one is fine . . . please, whichever is available sooner, even if there is a charge."

"Okay, I will contact you again when a room becomes available."

The wife rises up from her stool as if to depart, but her daughter squeezes in another question. The wife sits back down. "Can you give us an estimate? When

we look at his condition, we feel he doesn't have that much time left. If possible, we would like to have him come while he is still conscious." The slight tremor and sense of urgency that had been in the daughter's voice throughout the interview was growing stronger.

"Well, let me see. It will probably take one to two weeks."

"If he can come even one day earlier . . ." The daughter chokes on her words and starts to cry. The doctor sort of cuts her off.

"I understand. We will do our best."

After the family leaves, the nurse comes back in and sighs, "It's looking grave [*kibishii*]."

ENTERING THE HOSPICE

In Japanese, the word *kibishii*, meaning "grave" or "severe," is a common euphemism for "close to death." Doctors gingerly explain to families that the patient's condition is becoming *kibishii* or that the amount of time left is *kibishii*. Staff might even refer to certain patients as simply a "*kibishii* patient." Yet the atmosphere of the hospice is far from just *kibishii*. Rather, many patients and family describe the hospice as a place where they feel "safe" (*anshin*), "relieved" (*hoto*), "at ease" (*raku*), and even "healed" (*iyasareta*). This is because entering the hospice is akin to reaching the summit of a mountain. Before entering hospice care, patients are faced with an uncertain future and a plethora of decisions to make. How much longer should they continue chemotherapy? Should they switch to a new treatment or medication? Should they get a second opinion? Should they go home or stay in the hospital? When curative treatment options have been exhausted, how long will they be able to stay in the hospital? Where will they go next? The anxiety that accompanies these decisions takes its toll and a patient's family can become desperate. In addition to the emotional pain of losing a loved one, family members are taxed physically as they juggle hospital appointments, work, and their own family's needs.

It is no wonder many patients and families feel great relief when they enter the hospice. Although decisions still remain, the goal is much clearer. Doctors can forgo curative treatments and focus exclusively on alleviating the patient's physical discomfort, usually quite successfully. As one hospice patient called Higashimoto-san explained to me:

The specialty at the hospital is treatment. That is their specialty. Here, their specialty is palliative care. [In the hospital] I had horrible bedsores and couldn't sleep at night. My *kokoro* was not calm. I came here and received different treatments and now almost all the pain is gone. With the pain gone, I am finally able to attempt to do more things. While I had the pain, to be honest, I had no desire to do anything. . . . Now I am [finally] able to become forward-looking [*maemuki*]. I have no complaints.

As Higashimoto-san explained, one of the hallmarks of hospice care in Japan is helping dying patients feel a deep sense of calm in the days leading up to their death. While many of the day-to-day activities in the hospice are centered on palliating the patient's physical pain, the next important thing they can do is to help patients "be themselves" as they approach death (*jibunrashiku shinu*). But of course, it is not easy. Great emotional labor is involved. As nurses and doctors interact with a wide variety of patients at different stages of their illness, hospice workers are required to manage their emotions in front of patients and their families to demonstrate how much they care for and value the person dying in front of them. Good bedside manner is fundamental to all medical practice, but is felt to be particularly important at the end of life when patients feel especially isolated and may doubt the worth of continuing to live. This broad care that empathizes with and supports the heart of the dying is commonly referred to as *kokoro* care.

KOKORO CARE IN THE HOSPICE

Kokoro, a word that signifies the mind, the heart, the will, and much more, is notoriously difficult to translate into English.¹ It also commonly serves as a referent to the "self." For example, the phrase *kokoro bosoi*, meaning to feel lonely or without support, literally means "thinning of the heart." References to the *kokoro* is ubiquitous in Japanese culture, and in new religions, for instance, where the *kokoro* is the site of self-cultivation, an object to be purified, and a source of power.² In the Buddhist context, the *kokoro* is often treated as the locus of moral personhood. For example, in Japanese prison chaplaincy, the *kokoro* becomes a source of trouble through neglect; it is something that needs to be rectified or healed. Accordingly, Buddhist prison chaplains interpret the crimes committed by the incarcerated as bad karma, and their job as chaplains is to rectify the *kokoro* of the prisoners they work with to help expunge the bad karma.³

The importance of the *kokoro* as a site for religious sensibilities has become more apparent in contemporary Japan as many have shunned religious language that feels threatening. This is seen, for instance, in one of Japan's longest-running national television programs, *The Age of Kokoro: Religion/Life* (*Kokoro no jidai: Shūkyō/jinsei*). This program, which began in 1962, was originally named *The Time for Religion* (*Shūkyō no jikan*); it changed to its present name in 1982. The weekly program features interviews with religious figures, philosophers, social activists, educators, and on many occasions, hospice workers, to discuss religious wisdom and celebrate stories of human resilience and the overcoming of life challenges. As Mitsutoshi Horii points out, the replacement of religion (*shūkyō*) with *kokoro* in the program's main title represented a softening and broadening of religion, which was likely made with the intention of extending the scope of its content and viewership. Horii also notes that while only 28% of Japanese surveyed

in 2013 affirmed that they had a specific faith or belief, 66% felt that it was important to have a religious *kokoro* (*shūkyōteki na kokoro*).⁴

In hospice care, however, caring for the *kokoro* takes on a different nuance. It usually means to simply treat the patient as a person—in other words—holistically. It means to look beyond a patient's physical or medical needs. It refers to a care for the inner self, which includes both the mind and spirit. In theory, *kokoro* care is broader than spiritual care since the latter is focused on care for the "spirit." In my interviews, chaplains, nurses, and doctors all agreed that *kokoro* care denotes a broader set of practices that provides the foundation for spiritual care. But in practice, *kokoro* care also effectively doubles as spiritual care. While spiritual care is traditionally associated with care for a patient's religious or existential pain, in the absence of such symptoms hospice workers often focus on caring for the *kokoro*.

INITIAL EXAMINATION

Since most hospices in Japan have a long waiting list, a new hospice patient is received almost immediately after a bed opens. Shortly after the new patient has settled in, the attending doctor and nurse visit the patient's room for an initial examination. The physical examination is fairly simple. The doctor will listen to the patient's heart and lungs, examine the patient's eyes and mouth, and check the feet for swelling to measure blood circulation. Next, if the patient is still capable of speaking, the doctor will ask a number of questions, like: "What hurts the most?" "On a scale of one to ten, how much does it hurt?" "Does anything else hurt?" If the patient cannot respond or is suffering from dementia, the attending family members will answer for the patient to the best of their ability. After ascertaining the extent of the patient's pain and discussing possible treatments, the doctor then confirms the patient's awareness of his or her own condition: "Do you know the name of your illness?" "How much were you told by your previous doctor?" Finally, the doctor will ask the patient how much he or she wants to know about their prognosis, a delicate procedure known as informed consent.⁵

One technique I observed of broaching the subject of informed consent with patients in Japan involved the use of hypothetical patient types. Instead of directly asking the patient, "How much would you like to know?" the doctor provides the patient with a set of choices: "So in regard to being informed about your illness, some patients would like to know everything down to the last detail, while others are content to leave most of it to the doctor [*omakase suru*]. Which type of patient are you?" Answering this question is not always easy. For example, Kanedasan was a forty-nine-year-old patient who mulled over the question for a while before replying: "I used to be the type who wanted to know everything. However, as things got worse and my previous doctor told me the end . . . [here, she started

to choke up] is near, I don't care as much now." As Kaneda-san's family members also began to get teary, the doctor gently reassured them that he would take great care to make sure that she felt as little pain as possible throughout her stay.

After the initial meeting with a new patient, hospice staff excuse themselves from the room and meet with family members separately. At this time, the doctor attempts to gather additional information from the family's perspective. For example, in the case of Kaneda-san, the family shared how she never complained about her pain for fear of being bothersome (*meiwaku*) to her caregivers. She did not even mention the pain from her bedsores until her sister discovered them. The family also explained that Kaneda-san felt guilty about dying before her father, since this meant that the responsibility of care for her aging father would rest entirely on her sister's shoulders. As family members spoke through their tears, it was obvious that they were very pained by how Kaneda-san was still putting her family's needs ahead of her own. In fact, Kaneda-san had once told her family that she was giving up eating so that she could die sooner and become less of a burden. To her family's relief, once she found out that she would be able to enter the hospice, she began to eat again. The doctor finished the meeting with Kaneda-san's family by gently but plainly explaining that her condition was very *kibishii*. As the patient's father and sister continued to sniffle, the doctor tried to end the interview on a positive note by explaining again how the staff would be doing their utmost to make sure she didn't experience any physical pain during her stay. Medical control of her physical pain was one of the few promises the doctor could make in light of the many unknowns about how the short remainder of Kaneda-san's life would unfold.

Controlling physical pain is always the first priority of hospice staff. The founder of the modern hospice movement, Cicely Saunders, once explained that if she were a patient in pain, "the first thing I would want is not for an experienced psychiatrist to listen to my irritated feelings or a chaplain to pray that my pain will go away quickly."⁶ When a new patient is brought in, the first goal is to make sure that physical pain and discomfort is palliated as soon as possible. Without caring for the physical pain, spiritual care cannot even be considered.

In some cases, however, physical pain can also be a source of what appears to be spiritual pain. For example, one doctor shared a story about a patient who was extremely difficult to deal with. He constantly lashed out at his family and the hospice staff and declared every day that "he wanted to hurry up and die"—a statement that, for many professionals involved in spiritual care, suggested spiritual pain. But during the course of his stay, the medical staff made several medical adjustments, including a decision to use a nasogastric tube to help relieve some of his symptoms. When this helped relieve his discomfort, the patient was a changed man. He became a model of gratefulness and began to frequently express how much his family and other caregivers meant to him. As this patient's doctor reflected on this episode, she noted that what looks like spiritual pain could sometimes simply be a side effect of physical pain.

STAFF MEETINGS

The first shift report (*mōshiokuri*) in the hospice typically takes place around 9 a.m. The doctors, nurses, pharmacist, social worker, and chaplain gather in a room adjoining the nurse station while the night shift rattles off a rapid-fire report on the patients' conditions and whether anything notable occurred during the night. The patients' names are neatly arranged on a printed handout. The handout also lists the type of cancer they have right next to their name. Everyone looks down at their patient list as the nurse speaks.

Suzuki-san (ovarian) arrived yesterday. Can't eat.

Genmoto-san (breast) is taking Betanis. Needs help with the toilet. Requires at least two nurses. Has strong delirium. Her delirium has gotten progressively worse since her husband's recent death. She is a little senile and has probably a month left.

Arima-san (lung)—we did a rescue [dose] during the night. Switched to IV and is dozing. Some nausea. Her husband wants to feed her, but we are stopping her food.

Wakayama-san (ovarian) is taking Dormicum, wants to sleep more.

Matsui-san (colon) has maybe a week left. No food. No pain. Some communication. Mostly sleeping.

Soga-san (stomach) is as usual.

Uchida-san (colon) is doing better. Eating a third of her food.

Natsume-san (esophagus) is delirious and showing apnea. Lasting out the week is difficult (kibishii). Her family is okay with it, saying: "It can't be helped." Natsume-san herself is calm.

Kuribayashi-san (breast) is getting worse. She is still sitting up and using the internet though.

Akita-san (lung) is doing well.

Hirai-san (breast) vomits her food. No big change.

Although the core of the report is an overview of patients' physical symptoms, occasionally, there is an extended discussion of other issues. For example, staff members also consider the patient's family and financial situation, or reference the daily activities of patients. "A-san was pretty tired from visiting with family yesterday." "B-san couldn't sleep and visited the chapel early this morning." "C-san's wife's birthday is in October—he probably won't last that long, but can we help him make a birthday card?" In general, however, nonmedical updates are reserved for later discussion during the workday or in private exchanges. As nurses return to the staff station after the report, there is often an outpouring of conversation as they informally exchange information about patients or pull a doctor aside to discuss a specific issue.

The next time the hospice team gathers together is during the afternoon conference; this may be held daily or as seldom as once a week depending on the hospice. Its purpose is to exchange information and to formulate care plans for patients at a depth not possible during the morning or evening shift reports. Sample topics include discussions about the appropriate titration of drugs, whether to allow a patient to go home for the weekend, what to do with a patient who won't stop pushing the nurse call button, and how to explain a care plan to family members who felt medication was actually making the patient weaker.

Staff also use these meetings to take time to reflect on and evaluate their care for past patients. During an afternoon conference at a Protestant hospice in Kyūshū, the hospice team discussed Fukuda-san, a woman in her mid-seventies, who had recently passed away. During her final days, Fukuda-san seemed distressed and repeatedly asked the staff to raise her sedation levels and to "let me sleep" even though the amount they had given her was appropriate for her pain. Suspecting a deeper reason behind this request, the nurse consulted with the chaplain who initially expressed hesitation about raising her level of sedation since there seemed to be no obvious medical reason. He worried that she might be relying on the sedatives to overcome some sort of spiritual pain. Raising her sedation would also mean fewer chances for her to converse with her family. But when they consulted with Fukuda-san's daughter, she asked the staff to respect her mother's wishes. The daughter informed the staff that her mother was the type of person who liked to be in command of a situation and the adjustment of her medication was one of the last ways she could exert control over the end of her life. Even though the daughter valued being able to communicate with her mother, she explained how even more painful it was for the family to see her mother waste away in a manner that "was not herself." Ultimately, the doctor agreed to slowly raise her sedation level and she passed away shortly after that.

The staff at the afternoon conference now discussed whether raising her sedation levels had been the right decision. The chaplain stated that in light of Fukuda-san's wishes, he ultimately agreed with the doctor's decision. As he noted, this was not really a case of trying to stifle the patient's spiritual pain through oversedation—an action he would normally oppose. Rather, it represented a situation where the patient simply wanted to *be herself* by retaining control over her treatment until the very end. In this case, the chaplain argued, it made sense to respect her wishes and allow her to receive a deeper sedation even if her physical pain levels did not warrant it and it could mean fewer opportunities for communicating with her. Another doctor reaffirmed how Fukuda-san was an exception to the principle of not sedating patients without an underlying medical reason. He was careful to point out that sedation should never be used by staff to avoid the discomfort of watching a patient suffer spiritually. In his view, this was what spiritual care was for and what made the hospice distinct from regular medical care. He observed that their job as hospice professionals was not to shrink from suffering

or to sedate patients for the staff's convenience. Ultimately, in his view, this case helped remind them of the challenge in finding a balance.⁷

The case of Fukuda-san illustrated how spiritual care could potentially be at odds with other types of care. For example, if she was tired of wasting away in bed and simply wanted a higher level of sedation to forget her daily misery, most staff would rightly feel uncomfortable acquiescing to her request. If the true issue was physical discomfort or pain, it may have been reasonable to help her "sleep." But from the perspective of hospice workers who are committed to spiritual care, sedating her without medical reason might have failed to address a potential spiritual pain that might be the real cause of her misery. However, after learning more about the patient and realizing that it was her inability to control her sedation levels that prevented her from "being herself," this tension was resolved to everyone's satisfaction.

PATIENT ROUNDS

One morning, I followed Dr. Kuroda as she did her rounds. The first patient we visited was Arima-san, a female patient in her seventies, whose hands and feet, as we had just learned during the morning shift report, were getting colder. This was not a good sign. When we entered her room, we could immediately see that her breathing was labored. She had lung cancer and one lung had completely collapsed, causing her chin to jerk up with each shallow breath. An oxygen mask covered her mouth and helped her breathe. Her husband was sitting by her side and occasionally reached under his glasses to dab his eyes with the corners of his handkerchief. Dr. Kuroda gently took Arima-san's hand, stroked it, and softly greeted her. She then explained to the husband that even though the jerking of her chin looked painful, it was involuntary at this stage and did not necessarily mean she was in pain. "Please let us know if you see her furrowing her brow or anything else that might indicate pain and we can give her some more medications by IV." She gently uncovered the patient's feet and felt them in her hands. "Still warm." She then addressed Arima-san with some encouraging words: "Your son will arrive in a little bit." As the doctor prepared to leave, Arima-san's husband asked her, "Is it possible that her condition will take a sudden turn?" Dr. Kuroda replied, "I'll explain later."

After we left the room, I asked Dr. Kuroda what she normally says to patients and their families at this stage. "There isn't much I can say to the patient. I just make sure they are not in pain and try to comfort the family by letting them know that despite their appearance, they are not necessarily in pain. I also tell them that their presence beside the patient is the best medicine we can give." After we walked back to the nurses' station, she conferred with the attending nurse. "Arima-san probably has only a few hours left. Let's call her son and see if he can hurry."

I asked what medications she was giving Arima-san. "Mostly morphine," Dr. Kuroda replied. She was also on another medication to help with nausea and

had been taking steroids (although she was off them now), as well as sedatives like Dormicum and Seconal to help her sleep. Dr. Kuroda explained that in her experience cancer patients typically died in one of two ways. They could stop breathing (for example, in the case of lung cancer), which was then followed by cardiac arrest. Arima-san was likely to follow this pattern. Or they slowly weakened to the point that they could no longer eat. In some cases, when a patient has ascites, dying may take even longer due to the fluids trapped in the body, which contain nutrients. According to Dr. Kuroda, one patient in their hospice lasted for a month, living entirely off the fluids produced by his body. Most doctors prefer to stop giving food and liquids to patients at the end, since it causes them unnecessary pain. The nutrients often go straight to feeding the cancer anyway. Drinking liquids can also increase the amount of phlegm in the throat, which is difficult for weakening patients to cough up. However, these medical realities must also be balanced with the wishes of family members who can't help but feel that their loved one is getting weaker without food or water.

Dr. Kuroda went back to Arima-san's room and motioned to the husband to join her in the hallway. She asked when his son would arrive. "He's on his way," he replied. She then addressed the possibility of a sudden turn in his wife's condition. She explained that at this stage, a change for the worse could happen at any moment and recommended that he gather the family right away. "I think they can come this afternoon," the husband suggested. The attending nurse interjected softly but urgently, "It is a matter of hours and so this afternoon might be . . ." The husband was taken aback. His face showed that he was just beginning to register that the end had finally come. "Okay," he said. "I'll call them right now."

Leaving Arima-san's husband behind, next we went across the hall to visit Kuribayashi-san, a female patient in her mid-sixties who had breast cancer. Before we entered the room, Dr. Kuroda mused out loud, "Breast cancer can really take a long time." When we entered her room, Kuribayashi-san was reclining on her bed with an oxygen tube under her nose. In contrast to Arima-san, she was very alert. I marveled as Dr. Kuroda quickly changed from the thoughtful and somber demeanor she had maintained with the previous patient to a joking manner. We both laughed as Kuribayashi-san referred to her scheduled bath as a visit to "the hot springs." She was very sharp and witty. I learned that she liked to use the internet to order various things she fancied. She sometimes even ordered takeout meals to be delivered to the hospice, including from Mos Burger, a Japanese hamburger chain. This resulted in much laughter among the staff, since nobody in the hospice had any idea that this particular restaurant chain did deliveries. On another occasion, she purchased several large electric hotpots online and then invited the hospice staff to join her for a hotpot party in her room. A photo of the party was pinned to the bulletin board by her bed, next to several other photos taken during the hospice Christmas party. As we spoke, Dr. Kuroda joked that since Kuribayashi-san was always cheering her up, she was not sure, between the two of them, who was the real doctor.

Next, we visited Soga-san, a female patient in her mid-eighties, who was suffering from stomach cancer. She looked a little surprised when she saw my foreign face, but relaxed once she heard that I was fluent in Japanese. She began chatting about when she first saw Americans after the Second World War. She was a teenager when the war ended and she recollected how at the time, pretty girls were told to smear charcoal on their faces so that American soldiers wouldn't approach them. "I didn't need to since I was homely anyway," she said modestly. Dr. Kuroda and I hastily disagreed. She had learned a few English phrases as a girl during the American occupation, including: "I can't speak English." As I complimented her on her pronunciation, she noted that without a language barrier, foreigners felt much closer. As a matter of fact, she admitted that I was the first foreigner she had ever spoken to. Inside, I knew I was also the last. I told her it was an honor to meet her. As we left the room, she made an effort to sit up in bed and thanked us for coming. "Please come again."

The next patient we visited was Matsui-san, in her late sixties, whose colon cancer was pressing on her spinal cord and affecting her nervous system. She constantly felt a burning or tingling sensation in her leg. Since morphine is less effective for nerve pain, Dr. Kuroda was treating her with analgesics and a few other drugs that were used to alleviate spasms. When we entered the room, she was lying on her bed. Her brother and sister sat by her side while the TV played at a low volume in the background. She had received some aromatherapy treatment in the morning and her nails had been painted a nice pink color. The bright nails stood in stark contrast to her gaunt frame and drawn skin. Her mouth was involuntarily cracked open, showing her teeth in a perpetual smile. She could not voice words anymore, but she was still alert and could clearly follow everything the doctor said to her.

After a short visit with Matsui-san, we went and peeked in on Arima-san again. By now more family members had arrived. Her breathing was slowing; with every inhalation she made noises in her throat. Her family was becoming quite teary. We left the room.

HELPING PATIENTS FEEL VALUED

And with that, the morning had come to an end. Dr. Kuroda went to her desk to eat lunch, and I went to the cafeteria downstairs. As I admired the lunch of the day, a bowl of steaming rice topped with tasty tempura, I wondered how hospice staff were able to compartmentalize their work. How could I enjoy the lunch set before me when Arima-san was gasping for breath upstairs? How do hospice staff balance their feelings while going so quickly from one room to another? I remembered the advice I had received when I worked as a chaplain. "Before you go into a new room, take a moment and clear your mind of your visit with the previous patient. You don't want to bring your feelings from a prior patient into the room with you."

As Arlie Russell Hochschild explains, emotional labor requires workers to "induce or suppress feeling in order to sustain the outward countenance that

produces the proper state of mind in others.”⁸ In her study of how flight attendants attend to the stress of dealing with rude or exacting passengers, Hochschild notes that airline workers are trained to manage their feelings carefully, smiling always, even when they are seething inside. Hospice workers also engage in this type of intensive emotional labor—only the stakes felt higher. Dr. Kuroda’s ability to shift from a somber, sympathetic conversation with the family of Arima-san who was on the verge of dying, to a light-hearted, carefree conversation with Kuribayashi-san was no easy task. Since *kokoro* care is largely about *how* one engages with patients, emotional labor becomes indispensable to its practice.

Although hospice doctors and nurses spend a good part of the day helping to alleviate physical pain, ensuring that patients are comfortable, and communicating with family members, this is not to say that they do not see themselves as also providing *kokoro* care at the same time. For example, adjusting or changing a patient’s morphine or fentanyl titration to relieve pain, or allowing the patient to exercise control over their level of sedation, were seen as important ways to let the patient “be themselves.” This in turn communicated to the patient that they were highly valued and that their lives still had meaning—a kind of *kokoro* care. Doctors and nurses also tried to use small talk and compliments during their rounds to foster intimacy with patients, letting patient concerns resonate in their hearts. Other times, they would just sit for a time next to semiconscious patients and stroke their hand as they struggled to breathe. As one veteran nurse explained, “Even now, when I get questions from patients, I still don’t think there is a right answer for what to say or how to interact with them, and I still worry about this; I just try not to run away. I just try to listen carefully to them, and to interact in a way that shows that I’m trying my best to understand their feeling of suffering.”⁹ Or, as one doctor put it, the most important principle of spiritual care was simply to “turn one’s eyes to the patient’s suffering and to listen to them.”¹⁰ Another doctor suggested the importance of “letting the patient know that their existence is an indispensable necessity to you” (*hitsuyō fukaketsu na sonzai*).¹¹ In short, for many medical staff, the practice of spiritual care essentially meant communicating how much the patient meant to them. This communication was sometimes practiced directly, but more often indirectly, as hospice staff went about their daily duties mingling *kokoro* care in the interstices of other forms of care.

This understanding of spiritual care appears broader in definition than the more religiously inflected forms of spiritual care such as prayer, provision of religious services and sacraments, or encouragement through scripture. But since most Japanese patients are not very religious anyway, showing the patient how much they are valued through *kokoro* care was seen by most doctors and nurses as essential to the practice of spiritual care. *Kokoro* care was not seen as a substitute for a kind of spiritual care that was predicated on a religious approach, but rather was a part of it. This close connection between the *kokoro* and the religious dimensions of hospice care can be traced back to the early days of the Japanese hospice

movement, when the religious dimensions of hospice care were even featured in the news media with reference to their ability to provide “*kokoro* care,” as well as “*kokoro* support,” and “*kokoro* medicine.”¹²

SAYING GOODBYE

No sooner had I finished reflecting on the morning when one of the doctors peeked into the cafeteria, motioned to me, and curtly said, “It’s time for final care” (*ima, mitori*). I quickly returned to the ward and found Dr. Kuroda at the nurses’ station. She was just about to go look for me. Arima-san had passed away. The nurse explained to us that as Arima-san approached the end, it looked to those in the room that she had mouthed the word “water,” and so family members took turns swabbing her mouth.¹³ About twenty minutes later Arima-san stopped breathing. I now went with Dr. Kuroda and the nurse into her room. It was filled with her family: her husband, children, and their spouses. Everyone was weeping. Arima-san’s husband sat on one side of her bed and kept calling out her given name. “Michiko! Michiko!” Dr. Kuroda went to the other side of the bed, took Arima-san’s hand, and addressed her gently: “Please allow me to conduct your final examination.” She checked her chest for a heartbeat and confirmed that she had died. “We have confirmed her death at twelve o’clock, forty-two minutes, and thirty seconds.” Both she and the nurse then deeply bowed from the waist to the patient for about ten long seconds. After bowing, Dr. Kuroda addressed the now silent patient one final time. “You did a great job. Thank you for your hard work.” The nurse then encouraged the family to surround the patient and say their goodbyes. As we left the room and walked back to the nurses’ station, both Dr. Kuroda and I were silent. Finally, as she sat down on a stool and opened the patient’s chart to make the final entries, she commented: “Since the family was crying that much, they must have really loved her.”

When a patient passes away, the last entry on their medical chart often simply notes that they have been “discharged” (*taiin*) from the hospice. For most patients, death is the only way leave the hospice behind for good. Only the power of death can stop their cancer. After the doctor confirms the patient’s death, family members are given some time to say their goodbyes in the patient’s room. In the meantime, the funeral home is called, and nurses discreetly help the family tidy up the patient’s personal possessions. Before the patient is discharged, the hospice may also conduct a small “goodbye ceremony” (*owakare-kai*). This ceremony is optional, but many families welcome it. The ceremony is usually held in the patient’s room or in the hospital mortuary (*reianshitsu*). At Christian hospices, it may also take place in the hospice chapel in the rare case that the patient was a Christian. At a Buddhist hospice I observed, the ceremony was held in a room called a Vihāra hall, which contained a Buddhist altar. For example, of the seventy-eight patients who died between April 2010 and August 2011 at this Vihāra

ward, forty-eight (63%) of families requested a goodbye ceremony.¹⁴ But this also depended on the time of day when they died. Eighty-nine percent of patients who died during the day received a goodbye ceremony, while only 46% of patients who died during the night received a goodbye ceremony. During this ceremony, the patient's bed was placed in front of the Buddhist altar. A favorite item of the deceased, such as a family photo, was also placed on the altar. On one occasion, a Vihāra priest placed a can of coffee on the altar in memory of a patient who had liked to frequent the hospice vending machine in pursuit of some afternoon caffeine. At Christian hospices, the goodbye ceremony invariably opens with a hymn, such as "What a Friend We Have in Jesus" (Itsukushimi fukaki), while at Buddhist hospices, priests will recite a sutra.

During the goodbye ceremony, the patient's attending doctor, nurse, the chaplain, and other staff take turns sharing their memories of the patient. This is also a chance for the family to thank the doctor and nurses for their care. When the funeral company workers arrive, they carefully transfer the patient to their own stretcher. Although the deceased's face is normally covered with a white sheet, some hospices make a point of leaving the patient's face uncovered. This is to emphasize that death is not something to be hidden. Some hospices also purposefully take the patient out the front door of the building instead of the traditional back door.

LEAVING THE HOSPICE

As the funeral workers wheel the patient outside to the hearse, I join the hospice staff who quietly stream behind the rolling stretcher. When we exit the hospice doors, we are blinded for an instant by the bright sunlight, and I try not to sneeze. The patient has been covered with a special quilt that was made by hospice volunteers. The funeral workers take the quilt off the patient and replace it with their own blanket. Just as they lift up the quilt, however, the wind blows aside the sheet that was pulled over the patient's face, exposing her pale skin to the bright sun. The men quickly cover the patient's face, give an apologetic smile, and hand the folded quilt back to the hospice staff.

They load the patient into the hearse and one of the funeral workers hands the bereaved husband his business card with a map to the funeral home on the back. The husband looks confused about the location, but the worker reassures him by saying that he can just follow one of the other funeral workers who came in a separate car. The hearse leaves first, and as it pulls away, all the staff bow very deeply from the waist and keep their faces down parallel to the pavement until they are sure the hearse is out of sight. When I peek up prematurely, all I can see is the glare of the hot sun reflecting off the white rounded backs of the doctors and nurses in their uniforms before me.

After the hearse disappears from view, the husband turns to the staff and tries to say a few final words of thanks. Unable to gather his thoughts, he instead bows deeply to the staff. We all bow in return, rounding our backs again until his car is out of sight. When his car disappears from view there is a collective sigh of relief as the tension breaks. Staff turn to each other and murmur thanks for each other's help. There are even a few smiles as everyone strolls back to work.

Once the patient has left the hospice, he or she is then transported by the funeral company to a funeral parlor or the family home where the body is washed and nicely clothed. This is followed by a wake and funeral conducted by Buddhist priests, unless the family belongs to another religious tradition, or prefers a non-religious ceremony. After the funeral, the body is taken to the crematorium and the ashes are eventually deposited in a grave at the family temple, or increasingly, in new communal ossuaries that are cheaper and more convenient. Memorial services at later dates are also handled by Buddhist priests.

After their final bows outside, there is usually little further interaction between the hospice staff and the family. If the patient spent a long time in hospice care, the family may visit the hospice again after some time has passed to show their thanks. Some hospices also arrange for yearly events where family members of patients who had passed away in the previous year can reunite with staff and reminisce together. Hospices sometimes cooperate with volunteer organizations to help arrange more regular gatherings for grief care as well.

THE AFFECTIVE DIMENSIONS OF SPIRITUAL CARE

Kokoro care in the Japanese hospice shows the importance of the affective dimensions of spiritual care. Although some patients do not hesitate to bring up cognitive questions that relate to an existential search for meaning in the face of death, the practice of spiritual care is also centered on simply making the patient *feel* valued and needed. This interaction between the cognitive and affective dimensions of spiritual care are nicely encapsulated in the Japanese understanding of the *kokoro*, in which the character for *kokoro*, read *xin* in Chinese, refers to the faculty for both thinking and feeling. This affective dimension of the *kokoro* can be traced to premodern Japan when the character *i* (Ch. *yi*), meaning "intention," was also commonly used for *kokoro*. Based on this history, Thomas Kasulis suggests that the *kokoro* could be defined as a "cognitive form of affective sensitivity."¹⁵ Even translating the Japanese *kokoro* as "heart and mind" is problematic, since it reinforces the dualism between the affective and the cognitive that are blurred in the word. English terms like "psyche," "soul," "anima," and "spirit," fall short in that they suggest substantial entities rather than a mode of relating or being in touch with something or being touched by it. When hospice workers stress the importance of caring for the *kokoro* of patients, one might say that this type of care has an

important *affective* function that makes patients *feel* valued. While helping patients work through existential questions about the meaning of their life or offering religious truths that might provide solace in the face of death may give some patients peace of mind, care for the *kokoro* also includes a wide range of mundane activities and interactions between hospice workers and patients that help the patient constantly *feel* their worth by letting them “be themselves.” This in turn communicates to the patient that they are highly valued and that their lives still have meaning—a kind of *kokoro* care that forms the foundation of spiritual care. In other words, while spiritual care is often articulated in terms of supporting a patient’s belief system, care for the *kokoro* does not clearly distinguish between supporting patients in their beliefs, their emotional sensibilities, or even their physical needs.