

## The Meaning of Spiritual Pain

Nakano Kōji (1925–2004) was a Japanese professor of German literature, literary critic, and bestselling author who was diagnosed with esophageal cancer in February 2004. In his *Cancer Diary*, published posthumously by his wife, Nakano details his experience of being diagnosed with cancer, the headache of finding a good doctor, and his struggle to decide whether to pursue aggressive treatment in order to prolong his life. As he grew increasingly frail, he also mused on what living meant in the face of death.

I have a house and trees in my yard; my wife and dogs at my side. I have books and the four treasures of my study [brush, ink, inkstone, paper]. In my daily life, these are an extension of my person. Through all of these my life is made up. Lose any one of these and it is not my life. If these are cast away, where is my life? Without reading, writing, conversation, walking my dogs, and such, my life does not exist.<sup>1</sup>

In these few lines, Nakano recognized that the meaning of his life was inextricably woven into the mundane; he did not look for meaning apart from or beyond his daily activities and relationships. This type of self-realization in one's work, hobbies, family, or other relationships is often expressed as a person's *ikigai*.<sup>2</sup> His simple pleasures *were* his life.

If Nakano had entered a hospice, his increasing inability to walk his dogs might have also been diagnosed as a source of spiritual pain. As Cicely Saunders put it,

The realization that life is likely to end soon may well stimulate a desire to put first things first and to reach out to what is seen as true and valuable—and to give rise to feelings of being unable or unworthy to do so. There may be bitter anger at the unfairness of what is happening, and at much of what has gone on before, and above all a desolating feeling of meaninglessness. Here lies, I believe, the essence of spiritual pain.<sup>3</sup>

In this passage, Saunders links the concept of spiritual pain to the “meaninglessness” that patients might feel when reflecting on their past, present, and future. In other words, as Nakano's condition worsened and his daily routines were

disrupted, the meaning and purpose that he drew from these lifelong routines were threatened. His life—as he previously knew it—could no longer exist.

This chapter reflects on the extent to which Japanese hospice patients grapple with this “search for meaning” at the end of life. Of course, each hospice patient is different from the next and nobody dies the exact same way. There is no common condition behind spiritual pain, nor is it always clear to caregivers what constitutes spiritual pain. Instead, as one might expect, Japanese hospice patients express a range of anxieties when facing the end of life—some of which is explicitly existential or religious, but for the most part is not. Through personal interviews with hospice patients and chaplains, I introduce a core tension that lies at the heart of the concept of spiritual pain. On the one side, I suggest that for most Japanese patients, spiritual pain is only rarely articulated in terms of a search for meaning, belief, or transcendence. In fact, many of the patients who come to “accept” their death claim to do so by letting go of the need to transcend their condition altogether—a response that accords with the general reluctance of many contemporary Japanese to turn to a particular religious tradition for soteriological guidance in life as well.<sup>4</sup> On the other side of this tension is the fact that hospice workers who are committed to providing spiritual care ultimately *do* suggest that a “search for meaning” can be latent, repressed, or sometimes just poorly articulated by Japanese patients. In their view, spiritual pain is like a submarine at sea. Even when you cannot see it, it might be lurking below. This tension can make it difficult for hospice workers to distinguish spiritual pain from more mundane needs. Like Nakano, patients’ questions about the meaning of their lives are often embedded in very prosaic concerns. Naturally, this has important ramifications for the practice of spiritual care since it makes it difficult for spiritual caregivers to distinguish between patients who might be experiencing some deep spiritual anxiety, and others who might—for example—be just having a bad day.

The difficulty in identifying spiritual pain impacted my interviews with patients as well. Few patients, if any, were familiar with the idea of spiritual pain. Even if they were aware of the word “spiritual,” they often associated it with ghosts and other paranormal phenomena. As a result, I could not ask patients directly about the kinds of spiritual care they received or spiritual pain they experienced. This was liable to create confusion. Instead, I communicated to patients at the outset of each interview that I was researching how the hospice provided *kokoro* care. Key questions I asked included: “What nonphysical anxieties or worries do you have about death?” “What supports your *kokoro* the most?” “Do you feel supported by religion?” In some cases, family members were also present in the room. While this might have influenced the responses of patients, I used it as an opportunity to interview family members as well. Sometimes my questions fell flat. Other times patients immediately grasped what I was interested in. The selections here represent what I believe to be the most lucid and direct patient responses to the key questions I posed.<sup>5</sup>

## THE FEAR OF BEING A BURDEN

Hara-san was in his late sixties and dying of liver cancer. When I met him, he had been in the hospice for a little over a week. As I walked toward his room with the head nurse, she mentioned to me that he took great pride in staying busy. He felt that his wife and daughter were less capable than he was at taking care of the many household matters that had arisen in connection with his impending death. As he approached the end of his life, Hara-san felt that it was his responsibility to make sure that all necessary arrangements were being made for his family after he died.

BENEDICT: So, let's start.

HARA: Ask me anything.

BENEDICT: First, could you explain a little bit about how you came to the hospice?

HARA: Do you need the specific dates or . . .

BENEDICT: No, not at all. Just the gist.

HARA: In the middle of last month, I started to feel unwell.

*[There is a knock at the door. A volunteer brings in an afternoon snack.]*

BENEDICT: So, in the middle of last month . . .

HARA: I started to feel unwell and I went to a local doctor who suggested that we look at my liver just to be sure. He then notified me that he could see a shadow in my liver. Not only that, but it was also a very large shadow. So, before I came here, I was introduced to Hospital S. When I called the hospital and explained my symptoms, they said, "That sounds serious, please come right away to the hospital by taxi." At Hospital S, the doctor did many tests like CT, MRI, and ultrasound. After reviewing the results, the doctor said to me, "Hara-san, would you like to know the true details of your diagnosis, would you like only your family to know, or would you rather not know anything and live peacefully? Which of these three options would you prefer? I told the doctor that I would like to know the truth and all the details. He asked me what I would like to know, and I said I wanted to know how long I had [to live] and what my symptoms would be. He said, "Your life can no longer be saved. You are beyond receiving treatment since the cancer has proceeded into your bloodstream." *[Eight seconds of silence.]* "You probably have about three months left."

Then I had the doctor explain the symptoms properly. This was my wish. In the three months that remained, there were many things I could do for my family—things I did. I took care of my finances. I changed the *tatami* mats and took care of the piano. I haven't finished [renovating] the bathroom and bath yet, but I was able to make arrangements. As for renovating the house, I had ignored this for a long time because of the cost. I thought I would put it off until later. But I couldn't wait any more,

and so I called a company, and we were able to make arrangements. We set up a plan. Well . . . I was hoping we could at least get an estimate and draw up a contract, but we just entered the rainy season.

BENEDICT: Yes, it did rain yesterday.

HARA: During the rainy season, very few people request construction. The reason is because if it is humid when you are painting . . .

BENEDICT: Ah . . . that can't be good.

HARA: If the paint doesn't dry properly, about three years later stains will appear. That's why . . . but the thing is, you need scaffolding for painting. You need it to climb up and paint . . .

[His cell phone rings.]

BENEDICT: Please, go ahead.

HARA: No, I'll turn it off. Hello? I'm being interviewed right now so I'll call you later . . . yes. [click.] Excuse me.

BENEDICT: No, no, not at all.

HARA: And then . . .

BENEDICT: The scaffolding . . .

HARA: The scaffolding costs ten thousand yen a day. So then, if it starts to rain after they set up the scaffolding, the workers lose money. They need the scaffolding, but the cost is borne by the company. And so, the company asked if I could wait until the rainy season ended and do the house renovations in August. Because of this, I don't think there is enough time to finish the contract. But if the contract holder will not last until August, and the contract holder becomes a deceased person, all kinds of legal problems ensue. So, we decided to put the contract in my wife's name from the start.

[Five seconds of silence.]

BENEDICT: You have been making all kinds of preparations . . .

HARA: I have been most vigorously active! [Laughter.]

BENEDICT: You sure have!

HARA: Now . . . what was it I was meaning to say . . . um . . .

BENEDICT: How you got to this point . . .

HARA: That's right. So, as I accomplished these different things, the burden on my *kokoro* became lighter and lighter. So now, my mental state [*shinkyō*] is such that I feel like I can die anytime. You see, I'm not afraid of death a single bit. Not a single bit. The only thing is . . .

[Five seconds of silence.]

HARA: I don't want to die in a pitiful manner. For example, please excuse me for using the word "pitiable" [*nasakenai*] to describe this, but when you

have something like a stroke, even if you survive, you can't communicate your intentions. You become a great burden on your family. This is why I'm glad I have cancer. With cancer, they tell you how long you have, and during this time, you can do all kinds of things. I'm in my late sixties, and I still have strength. My wife is several years younger and still has energy and physical strength. But if this happened five to six years from now, I wouldn't be so active, and even my wife would not be able to move the way she can now. So, I think all of this might have been the will of the god(s) I cannot see [*me ni mienai kamisama no omichibiki*]. I am quite thankful. I'm very glad it turned out this way. The burden of my *kokoro* has become very light. My *kokoro* has become . . . it loses its desires and now it feels perfectly clear.

BENEDICT: So, at first you felt that you needed to put things in order . . .

HARA: I was anxious. I had no leeway. So even when I was asked to do various things, I declined everything and just worked vigorously on household matters. After all, this is the most important thing.

BENEDICT: I see, I definitely understand. So, as you went about working on your home, the burden on your *kokoro* gradually lessened.

HARA: Yes, it lessened. I am now comfortable [*raku*].

BENEDICT: So, did you have any other particular kinds of worries [*fuan*] or stress [*sutoresu*]?

HARA: Umm. Nothing for now. Well, there is the issue of my grave. My child is still single. She—I have a daughter—will be turning thirty-five, and so even if I buy a grave, she will not look after it forever, and so after thinking it over, I decided to be buried in a grave where many different people are buried together and memorialized. Oh, and I have already gotten an estimate from the funeral company [*laughs*]. I have made every preparation possible! [*More laughter.*]

One of the most commonly held anxieties voiced by hospice patients in Japan is a strong desire to not become a burden (*meiwaku*) on others. As Hara-san explained, his first priority was putting all of his affairs in order before he died. As he accomplished these goals, which he had delayed for so long, the burden on his *kokoro* “became lighter and lighter.” It was clear that he derived deep satisfaction from tying up loose ends and making sure that his wife would not have to do them in his stead. He described these tasks to me with great pleasure, and our conversation was punctuated with laughter. He also felt thankful that cancer allowed him to stay independent longer than other incapacitating illnesses. For example, he described his mother, who became bedridden after a stroke, as pitiable. He even thanked the “will of the god(s) we cannot see” for his cancer that allowed him to avoid this pitiable state. Finally, he explained that he had chosen to be buried at an eternal memorial grave (*eitai kuyōbo*) instead of in a traditional Buddhist temple plot. Eternal memorial graves represent a relatively new form of communal ossuaries where memorialization rites are conducted by a third party (instead of by

living family members) for those who are buried there. This new form of burial is cheaper than purchasing an individual plot at a temple and ensures that the deceased will continue to be memorialized without placing a burden of obligation on surviving family members.<sup>6</sup> By choosing to be interred at an eternal memorial grave where Buddhist priests would perform memorialization rites for him on the behalf of family members, Hara-san further demonstrated that he did not want to place a burden on his family after his death.

Hara-san's concern about becoming a burden reflects an idealization of a certain manner of death in Japan. As Susan Orpett Long has demonstrated, two dominant cultural scripts for an ideal death in Japan are *rōsui* (a gradual decline in old age), which provides time for the dying to arrange their family affairs and take care of loose ends, and *pokkuri* (a sudden death), which does not impose the burden of a long hospitalization on the family.<sup>7</sup> Notably, the idealization of these two contrasting types of death stems from the same rationale—a desire to not burden others. Although slightly removed from the hospice context, similar ethnographic work on the lives of the elderly also suggests that the anxiety felt by Japanese elders over becoming a burden on their families and communities is one of the key reasons for Japan's extremely high rate of elder suicide.<sup>8</sup>

Arita-san, who had stomach cancer and was in her late seventies, also described how entering the hospice had allowed her to avoid concern over becoming a burden on her family. During our interview, her daughter was also in attendance and chimed in with her thoughts.

DAUGHTER: I was taking care of my mother at home with the help of a home doctor, nurses, and caregivers, but my mother kept saying, "I'm sorry, I'm sorry [for being a burden]" [*mōshiwakenai, mōshiwakenai*].

ARITA: Being at home was emotionally difficult . . .

DAUGHTER: I was glad I could show respect to my mother [*oya kōkō*] by helping her and planned to keep doing so, but my mother is sensitive [*ki o tsukau*] [about being a burden]. She is even sensitive with the nurses. When a nurse comes, she feels that she needs to do whatever it is quickly since they are so busy . . . When I was at home, I would sleep next to her, but sometimes I would wake up in the morning and my mother would tell me her pajamas had gotten soiled. She asked me to wash them, and I asked, "How did you take them off?" I found out that [instead of waking me], she had struggled to take them off herself. I would say, "Wake me up! That's why I'm living here with you." [*Laughter.*]

Encountering Japanese patients like Hara-san or Arita-san who cite being a burden on their family, friends, and caregivers as one of their strongest concerns at the end of life is not surprising, nor unique to dying patients in Japan. For example, the fear of becoming a burden to others is known in the global parlance of hospice work as the patient's "self-perceived burden" (SPB).<sup>9</sup> What sets Japan apart from other hospice settings, however, is that physicians and nurses in Japan do

TABLE 1. Existential concerns of terminally ill Japanese cancer patients

Acceptance/preparation	25%
Relationship-related concerns Isolation Concerns about family preparation Conflicts in relationship	22%
Hope/hopelessness	17%
Loss of control Physical control (dependency) Cognitive control Control over future (uncertainty)	16%
Loss of continuity Loss of role Loss of enjoyable activity Loss of being oneself	10%
Uncompleted life task	6.8%
Burden on others	4.5%

SOURCE: Morita et al., “Existential Concerns of Terminally Ill Cancer Patients Receiving Specialized Palliative Care in Japan,” *Support Care Cancer* 12 (2004): 138.

not hesitate to indicate this self-perceived burden as a type of spiritual pain. Statements from patients like, “I want to die before I become a burden on others,” or, “I don’t want to cause anxiety and trouble to my husband” are believed to indicate spiritual pain.<sup>10</sup> In a survey by Morita Tatsuya, a veteran hospice physician and leader in Japanese hospice care research, he identifies seven categories for existential pain (*jitsuzonteki itami*), which he treats as synonymous with spiritual pain.

According to Morita, about a quarter of the eighty-eight patients interviewed by his team expressed an existential form of pain related to a general unpreparedness for death, while—as indicated at the very bottom of the chart—just under 5% of patients directly expressed a fear of becoming a burden on others. While the number of patients who fear being a burden on others seems low in this survey, this is partly due to the way the categories were set up. For example, 16% of the patients surveyed expressed concern about loss of control over their faculties, while another 6.8% of patients were worried about tasks left uncompleted, such as legal matters or funerary arrangements. These patients were likely anxious, as Hara-san was, that such factors would add to the burden they already saw themselves as posing for others. In addition, 22% of patients in Morita’s survey also indicated relationship-related “existential pain,” which included expressions of concern about their family’s preparation for their death. In effect, several of these categories doubled as expressions of concern about becoming a burden to immediate family members.

Classifying a patient's self-perceived burden as a type of spiritual pain stands in contrast to the ways spiritual pain is measured in the United States, where widely used surveys on spiritual well-being like the "Functional Assessment of Chronic Illness Therapy-Spiritual Well-Being 12 Item Scale" (FACIT-Sp-12) contains questions that asks patients to rate their feelings of inner peace, purpose, harmony, and meaning, as well as strength or comfort from religious or spiritual beliefs, but does not address the question of being a burden on caregivers.<sup>11</sup> This is not because American hospice patients do not worry about becoming a burden on others. They certainly do. But these types of concerns are less likely to be labeled as "spiritual" in nature.

Identification of the patient's self-perceived burden as a form of spiritual pain in Japan also raises questions. For example, it is not entirely clear how such anxieties might differ from the concerns that social workers or clinical psychologists on the hospice team are trained to deal with. Although the fear of being a burden on others could certainly bring patients to examine existential questions about the meaning and value of their life, such anxieties could also be generic expressions of concern by patients who care deeply about their families and simply do not want to be a burden on them. In this way, patient expressions of self-perceived burden cannot escape a fundamental interpretive ambiguity; they can be understood either as natural reactions to becoming dependent on others for end-of-life care, or as signifying a deeper existential insecurity in the face of approaching death. It is also not yet clear whether this concern is particular to hospice-care wards or also applies to patients who die at home. There may in fact be some self-selecting bias present, since there is a high probability that Japanese who are concerned about being a burden on caregivers would prefer to die in a palliative care ward rather than rely on family members to provide end of life care at home.<sup>12</sup> Either way, one possible reason why a fear of being a burden is sometimes considered a form of spiritual pain by Japanese hospice workers is the cultural importance placed on repaying social debts (*on*) and fulfilling obligations (*giri*). An inability to repay such debts could conceivably cause deep anxiety for patients to whom the fulfillment of these obligations helps give their life meaning, thus causing spiritual pain.

#### IT CANNOT BE HELPED

Many patients I spoke with suggested that the reason existential questions about meaning or purpose, or the afterlife, were less of a concern for them, was because they saw death as inevitable, and that worrying about it would not change anything. Patients described such questions as problems that could not be helped (*shiyō ga nai* or *shikata ga nai*; lit., there is no way [to solve it]). For example, Hara-san, who was busy tying up loose ends, had this to say when I asked him why he did not worry about death.



BENEDICT: Before, you said that you were not afraid of death at all . . .

HARA: Not at all. I've never feared it one bit.

BENEDICT: I see. That is remarkable.

HARA: As I said earlier, the only thing I feared was having a stroke or dying in a way that made me a burden [*meiwaku*] on others. I feared this before I became ill with this disease. I especially feared having a stroke, because that was how my mother died. She was restricted to her bed, and we couldn't understand her words. Since we were family, we could understand a little bit, but for the doctors and for herself, I think it was very painful. She couldn't get up, and she couldn't even turn over in her sleep. I think it was painful for her just to be living. You might even say, and I probably shouldn't say this, it was like being tortured before death [*laughs*]. Anyway, it was torture for her, and it was a great burden on the family. To think that I can go without this, I thank the gods [*kami ni kansha shiteimasu*]. Cancer is a wonderful disease [*laughs*].

BENEDICT: That is wonderful that you can be so positive. For example, some patients may fear what comes after death, or have similar kinds of anxiety . . . I hear this from time to time, but in your case, you don't seem to . . .

HARA: In my case, concerning the afterlife, since I have never gone there, I don't know. So, I believe there really is no point [*shikata ga nai*] to think about this. The only thing is, at the funeral, even if you have a grand funeral, many people will just talk about their business lives or catch up [with friends]. There are grand funerals where the deceased is not mourned, and there are also small funerals where the deceased is truly mourned from the *kokoro*. This is determined by one's actions while living. That is why I think that perhaps one's actions while living might be reflected in the afterlife—reflected in the *kokoro* of those who are left behind.

Here, Hara-san reiterates that his only real fear was dying in a way that would make him a burden on his family. With vivid memories of his own mother's suffering after her stroke, he is once again thankful to the gods that he can avoid such "torture." When I asked him about his view of the afterlife, he dismissed the thought that this would cause him to worry. As he explained, nobody has experienced the afterlife and lived to talk about it, and so there was no point in thinking about it (*kangaetemo shikata ga nai*). As far as he was concerned, the only afterlife he could control was how he would be remembered in the *kokoro* of those he left behind.

This stoic view of death was also reflected in my conversation with Yanagi-san, another patient who claimed death did not cause him any real concern. Yanagi-san was in his mid-seventies and had been struggling with stomach cancer for several years. According to the nurse, he was looking forward to talking with me. Later, I learned that our conversation was a virtual repetition of what he had spoken about with the chaplain earlier in the week. He had a piece to say and was

looking to share it with anybody who was willing to listen. When I entered his room, he was watching TV while lying on his bed in his pajamas.

YANAGI: I've really become amiable [*nagoyaka*], and I don't fear death anymore. Not at all. So even if I died today or tomorrow, I don't fear anything at all. I thought that I might be a little fearful at night when I'm all alone in the dark, but this didn't happen either.

BENEDICT: You didn't fear death in the past either?

YANAGI: No, no. I was a real scaredy cat.

Yanagi-san then began talking about how his illness had helped mitigate his fear of death. He pointed out that being forced to interact with many different people through his illness had made him a better listener. He admitted that he had originally been short tempered and would fight with his wife. But since being diagnosed with cancer, he had become a more understanding person.

BENEDICT: But regarding death . . .

YANAGI: So regarding [my not fearing] illness or death, I want to turn the question to you. How is it that I have become like this? I almost want you to point this out to me.

BENEDICT: Some patients say that they are fearful of suffering at the end, or of whether there is an afterlife . . .

YANAGI: You just need to make your own story [*monogatari*]. Leaving aside the question of whether this is a right or wrong approach, since I haven't been to the afterlife, nor returned from it, ultimately, I think it is fine to imagine for yourself what it might look like. That's what I plan to do. When this life is over, I believe there is a spirit world [*reikai*] somewhere in heaven where everyone is gathered. People from Europe, the Americas, and other places must all pass through this spirit world. The spirit world is a place of only spirits [*tamashii*]. Since there are no human bodies and just spirits, you don't need English or German or anything; everyone just speaks "spirit world-ish" [*laughs*] . . . Everyone will meet above the earth, and I'm sure there will be those who did some slightly bad things. But everyone just studies [*benkyō shite*] and after polishing themselves [*migaite*], a few years later they come back over here [to earth]. So, you see, I've never done religion or anything like that, but since this is what I think and plan to do, I don't have anything to fear . . . ultimately, saying that you are afraid because you don't know whether you will go to heaven doesn't help [*ittatte shiyōganai*]. You just need to think for yourself and make up your own ideal [explanation].

As I prodded Yanagi-san on whether death inspired any fear in him, he suggested that while in the past he thought that he might fear death, he no longer had such concerns. In fact, he had his own theory that in the afterlife all humans would be taken to a supernatural realm where they could practice self-cultivation to become better people before being reborn into this world. He did not claim that his theory

was for everyone. Instead, he thought that each person should make a story of their own liking to help mitigate fear of their postmortem fate.

Both Hara-san and Yanagi-san suggested that worrying about the afterlife was a futile exercise. After all, no one really knows what lies beyond death. However, in contrast to Hara-san, Yanagi-san had clearly devoted some time to thinking about this. Whereas Hara-san was more interested in discussing what he could control in terms of how he might be remembered by his family, Yanagi-san described his own theory about the afterlife with great gusto. It was less clear why—if he was truly unconcerned about death—he felt the need to come up with his own detailed theory about the afterlife. Yanagi-san had obviously devoted some thought to this issue and was eager to share his theory with both the chaplain and me. This seemed to indicate that while he was convinced that there was no point in worrying about what lay beyond death, this had not stopped him from thinking or wanting to talk about it either.

#### CORROBORATION FROM CHAPLAINS

When I inquired of hospital chaplains whether their experience tallied with my impressions that many patients seemed, at least on the surface, indifferent to religious or existential questions in the face of death, several readily agreed.<sup>13</sup> A chaplain at a Christian hospital in Tokyo put it this way.

In terms of spiritual pain, in my experience, most patients do not have large anxieties [*fuan*]. Instead, they mostly just talk indifferently about themselves [*tan tan to hanasu*]. It is hard to say if they have come to accept their death. Japanese are very ordered about these things. Many patients choose not to think about it and say it can't be helped [*shikata ga nai*]. They have made this their policy from the beginning. They see no point in worrying about it. In this regard, many patients do not have much inner conflict [*kattō*]. This point is driven home when we occasionally have Korean or Chinese patients. They are much more emotionally involved.<sup>14</sup>

Another chaplain put it more bluntly.

Japanese are very good at giving up [*akirameru no ga jōzu*]. For example, Kübler-Ross's model [of the five stages of grief] does not fit very well with Japan. For most Japanese, the final stage is not acceptance [*juyō*] but giving up [*akirame*]. They all say, "It can't be helped" [*shiyō ga nai*]. They do not try to figure things out. Many Japanese do not think so philosophically about these things. They will just say, "Such is life" [*jinsei wa sōyū mono ja nai ka*].<sup>15</sup>

When I asked yet a third chaplain what he thought of the notion that Japanese are "good at giving up," he began nodding vigorously.

Yes! Yes! That makes perfect sense. You know patients will change [*kirikaeru*] [at the end of life]! I think Japanese place a value on quitting, on seeing death itself as an end . . . For example, the suicide rate is high too. This is not the same as the Buddhist

understanding of nonattachment; rather, it is about not wanting anything and throwing away everything. There are many elderly [patients] in their seventies and eighties. They won't say a peep. They probably didn't live during a time where you thought a lot about the meaning of life or the meaning of death. It was Japan's period of economic growth. Housewives were immersed in the practical matters of day-to-day living and made great sacrifices for their family. When their body finally stops working, they accept it. It is the same for the men. When they lose, it is over.<sup>16</sup>

According to the first chaplain, very few patients voice large existential or religious anxieties. Or, at least, many patients choose to not dwell on anxieties that "cannot be helped." According to the explanations proffered by these last two chaplains, this ostensible lack of spiritual pain in Japanese hospice patients is partly due to a kind of stoicism in elderly patients of a certain generation, if not all Japanese. In particular, the last chaplain saw patients who lived through the Shōwa period (1926–89) as a particularly stoic generation that survived the political and economic turmoil of the Second World War and its aftermath and then worked tirelessly for their companies and country through the economic boom that followed the 1960s. According to this chaplain's narrative, many Japanese salary men were simply conditioned not to think (or were too busy to think) about the deeper meaning behind their overworked lives. Likewise, the chaplain believed that Japanese housewives, who were pressured to sacrifice their careers after marriage and toil at home for their husband and children, were conditioned to accept the unfairness of the gendered status quo. In this chaplain's view, these cultural experiences might have helped prepare Japan's wartime and early postwar generation to phlegmatically accept the sufferings that came from dying of cancer.

Notably, while the last chaplain also made a point of distinguishing between the tendency for patients to "give up" difficult questions at the end of life and Buddhist ideas of nonattachment, yet another chaplain suggested to me that the resignation he often saw in patients could stem from Buddhist influence. He shared a story of a married female patient in her early fifties who still had young children, and, in his view, had "lost hope." She explained to him, however, that she had lived her life with "resignation" (*teikan no omoi de ikite kimashita*).<sup>17</sup> He noted that this idea of "resignation" (*teikan* or *taikan*) is central to Buddhism in which it means to "see clearly" (Skt. *Darśana*).<sup>18</sup> In fact, the Japanese word *akirame*, or to "give up," actually stems from this Buddhist sense of the term, "to make clear" (*akiramu*). This helps explain the positive tenor of the claim "Japanese are very good at giving up," since "giving up" (*akirame*) and "making clear" (*akiramu*) are etymologically linked.

These chaplains' accounts, surveys administered by hospice doctors and nurses seeking to measure spiritual pain, and my own interviews with patients suggest that, for many Japanese, facing death only rarely prompted outward expressions of deep spiritual anxiety to those who were caring for them. For example, Morita's survey on existential pain, touched on earlier, suggested that the search for

meaning was not necessarily the most important “existential” issue for Japanese hospice patients. Of the seven categories that Morita established, only two, “hopelessness” and “acceptance,” seem directly tied to patient concerns over whether their life had been meaningful, the meaning of their current condition, or what meaning was left in the remainder of their life, which was assumed by Cicely Saunders to be important components of spiritual pain.<sup>19</sup> On closer examination, however, even these connections prove tenuous. In Morita’s survey, expressions of “hope/hopelessness” included patients who looked forward to spending time with their family but worried whether they would live long enough to see the “completion of a new house, birth of a child, the ballet performance of a grandchild,” or embraced hopes of “returning home and curing the disease.” Likewise, anxiety about acceptance of death typically included very general expressions of concern, such as “I don’t want to die” or “I fear that I am going to die.”<sup>20</sup> While such statements could signal deep existential fears, they are also quite vague and could refer to any number of nonexistential concerns, such as the fear of physical pain at the end of life, or disappointment over not being able to meet future grandchildren.

Taken together, these results suggest that very few Japanese hospice patients outwardly frame their concerns in existential questions about the meaning of their life or suffering, or what may lie in store after death. However, before we attribute this to some specifically Japanese culturally determined stoicism, as some of the chaplains I spoke to did, it is imperative to note that there are good indications that death anxiety of this sort may be less prevalent than one might expect outside of Japan as well. For example, Jonathan Jong and Jamin Halberstadt argue that in the United States there is little evidence to suggest that the proximity of death will heighten one’s anxieties about it—at least not at a conscious level.<sup>21</sup> In fact, one study of ninety-two terminally ill patients showed them to be less fearful of death than healthy individuals.<sup>22</sup> One explanation for this is that hospice patients come to see death as inevitable. As Jong and Halberstadt point out:

By far the most common reason given for their lack of fear was that death is inevitable. This is somewhat ironic given that many thanotocentric theories, and Terror Management Theory in particular, cite this exact aspect of death—its inevitability—as a prime reason to fear it . . . terminally ill and seriously ill participants likely appreciate the inevitability of death better than most, and yet they seem to have the opposite response: It’s going to happen, so why worry?<sup>23</sup>

Studies like these suggest that the infrequency of strong death anxiety among hospice patients is certainly not limited to Japan. While exploring the comparative aspects of death anxiety outside of Japan exceeds the scope of this study, it is worth noting this comparative context to emphasize that Japanese hospice patients are not conditioned by some “samurai-like spirit” that makes them oblivious to the fear of death. Although some chaplains suggested that a cultural stoicism might help explain why patients rarely voice existential or religious concerns, the relative

lack of heightened death anxiety in other cultural contexts suggests that other factors are also in play. Rather, my findings simply suggest that studying the minimal degree to which Japanese patients raise existential questions about “meaning” at the end of life may have important cross-cultural implications as well.

On its face, the paucity of Japanese patients who raise questions about meaningfulness undermines traditional definitions of spiritual pain that are centered on what Saunders and others have called “the search for meaning.” For many Japanese hospice patients, social and familial concerns often eclipse existential or religious anxieties about the meaning of their life, suffering, or questions about what comes after death. In order to seek relief from the anxiety that they are a burden on others, instead, many patients try to fulfill their social and familial obligations until the very end of life. This confirms how the practice of spiritual care in the Japanese hospice often goes beyond simply helping patients vocalize spiritual pain and addressing it through counseling or religious support. Rather, much of spiritual care is conducted in the margins of daily care, through supportive *kokoro* care that allows the patient to “be themselves” and feel valued by way of special events or even prosaic activities—an affective (rather than cognitive) approach to spiritual care that elicits less resistance from nonreligious patients.

#### DIGGING FOR SPIRITUAL PAIN

If, seemingly, only a small number of Japanese hospice patients articulate existential or spiritual questions about meaningfulness, guilt, the afterlife, or their relationship with some transcendent power, how necessary are chaplains? Could a clinical psychologist, counselor, or volunteer just as adequately care for patients concerns? More importantly, what does this say about the other side of the core tension in spiritual pain: namely, that spiritual care for patients should not only be available, but is also indispensable for most, if not all, patients, as chaplains, nurses, and doctors strongly insist?

One suggestion proffered by some chaplains to explain the lack of religious or existential forms of spiritual pain is that sometimes you must “dig” for it. In other words, although patients may not be fully conscious of their inner anxieties, they may still have them anyway.<sup>24</sup> To take the case of Yanagi-san, who claimed that he was not afraid of death at all, it was certainly possible that he was experiencing some sort of spiritual pain at a subconscious level—a form of spiritual pain that did not manifest itself through observable symptoms. As a matter of fact, even though Yanagi-san claimed that he did not “fear death,” he was also strangely insistent that patients should create their own narrative about the afterlife to achieve peace of mind. Yet, if Yanagi-san himself claimed to be unconcerned about death, on what basis could he be diagnosed as suffering from spiritual pain? Even if he had privately nursed such concerns at one time, if he had successfully coped and come to peace with these concerns in his own way, on what evidence could a

hospice worker claim that such a patient was still in need of spiritual care? This is a crucial point that gets to the core tension in the study of spiritual pain. From a medical perspective, without observable symptoms, it is hard to make a case for spiritual pain. At the same time, spiritual pain is not something that can be easily measured, like checking for a fever with a thermometer.

Most of the chaplains I spoke with in Japan believed that whether hospice patients expressed it outwardly or not, the majority experienced some degree of spiritual pain deep inside. Although chaplains admitted that only a handful of patients might openly display concern about meaning, guilt, or the afterlife, they also firmly believed that this indifference was only a facade and that in many cases, caregivers might be overlooking a hidden spiritual pain. In short, they expected that patients, and especially those of an older generation, would stoically repress their spiritual pain by claiming, "It cannot be helped." As one chaplain explained to me, sometimes you must dig for spiritual pain:

Sometimes I will ask a patient if they have any anxiety and they will respond, "Not really." But then I will start talking about things I might feel anxious about [in their place] and they will say, "Yes, me too!" Some patients will even laugh and say, "Oops! I did not mean to share that!"

You must look for it; patients won't bring it to you. You must dig around by asking about their condition, family, history, and hobbies and so forth before it comes out. I tell nurses to make sure they make the conversation fun, because it is a lot of work to uncover. You need to make sure the patient is enjoying the conversation.

Many patients will basically say they don't have any worries in particular, but when they say no, it doesn't always mean no. In the United States, they will keep passing you the mashed potatoes until you say, "No, thank you," and then they won't offer it to you anymore. But in Japan, you need to keep offering it, even after they say, "No, thank you," to make sure they aren't just holding back [*enryo*].<sup>25</sup> I sometimes will tell the patient, "You may not have any worries now, but if you do in the future, make sure that *you* call me." That way, the responsibility lies with the patient.<sup>26</sup>

As this chaplain explained, it was common for patients to conceal their fears. This meant that chaplains could not simply assume that an outwardly placid patient may not be working through some difficult questions. However, although this particular chaplain insisted that patients sometimes needed to be prodded to share their deep anxieties, she was also careful to point out that, in the enthusiasm for instituting spiritual care in Japanese hospices, there was also a very strong danger in trying to see spiritual pain where there was none.

Everyone wants to talk about how Japan is behind in providing spiritual care. They throw everything under the label of spiritual care. I think it would be great to have a presentation at a conference that talked about cases where they thought the patient was experiencing spiritual pain, but it turned out to be something totally different. I think everyone would get a kick out of that. Maybe a patient was anxious about dying, but after inheriting a large amount of money, all of a sudden, he or she stops

worrying! [*Laughter.*] [Cicely] Saunders was trying to emphasize the concept of total pain. We can't just take the spiritual part out and emphasize it. Sometimes the patient is just in pain. "Doctor, please give him some more medication!" It can be as simple as that.

I remember one patient whose grandson was competing in the national high school baseball tournament. The patient said that if his grandson's team made it to the finals, he really wanted to go watch the game in person. He could still walk, and so the whole hospice staff was cheering for the team to make it to the finals. The team was doing well, but shortly before the finals, the patient's cancer spread to his bones. He could no longer get up on his own. After the doctor explained his condition, he said he would just have to watch the finals on television. After this, he asked for a nurse to bring him his drawing materials and went about his hobby in an unperturbed manner.

But his nurse was very concerned that he might be feeling some spiritual pain due to this [disappointment] and kept checking in on him. She told the rest of the staff that she thought he might be trying hard to remain stoic in the face of this great disappointment. However, I was a little suspicious and thought it would be better to just ask the patient directly. I went and asked him directly how he felt after receiving such bad news. I also mentioned that the staff was worried that he was trying to stifle his disappointment. He laughed and said, "Oh, so that's why the nurse keeps checking in on me!" He then clarified his stoic reaction: "I'll explain why I'm not expressing anything. I am a Tenrikyō believer, and this supports me."<sup>27</sup> My *kokoro* doesn't easily become disturbed as others might expect. I don't think I will become like other patients."

As these stories show, assessing spiritual pain is a delicate task. At times patients might be reluctant to share their anxieties with the staff whose job is to support them. At other times, nurses or chaplains who are looking to provide spiritual care might be looking for spiritual pain where there is none. The Tenrikyō patient, for example, flatly denied that he was hiding spiritual pain. Instead, he credited his stoic reaction to his personal religious faith, which kept his *kokoro* from being disturbed.

In rare cases, an overzealous staff member could actually worsen the patient's condition by trying to probe too aggressively for spiritual pain. For example, a palliative care nurse who worked at a large hospital near Tokyo shared the following story with me.

At the palliative care ward where I previously worked, there was one staff member who felt a very strong need to provide spiritual care to patients. But in one case it made things difficult for a patient who was not seeking this type of care. I sometimes wonder if one should try not to be too sensitive about spiritual care; it sometimes feels like the medical worker is jumping to conclusions . . . I understand that the goal of saying you need to do this or that, and to make a manual for spiritual care is to make everyone more conscious about spiritual care and to help the many people who do not know how to provide it. But this staff member got caught up in practicing this and forced the patient to confront questions such as, "Why did you get



ill?" "Why are you here?" After being confronted with these questions, the patient became depressed and there was nothing we could do to help. The patient stopped eating, refused all treatments, and died about a week later.<sup>28</sup>

This disturbing anecdote demonstrates the care and sensitivity required of chaplains and other hospice staff who are involved in spiritual care. For example, relatively young patients, who might still have young children or living parents could be reluctant to discuss their spiritual pain because they did not want others to feel sorry for them. Patients of an older generation who adhere to more traditional values might also be reticent to share personal matters with an outsider. Sometimes gender differences could also play a role. One chaplain jokingly mentioned that if there was a patient who refused to see a chaplain, it was almost always a male in his early fifties.<sup>29</sup>

Even still, many chaplains insist that this does not necessarily mean that such patients are without spiritual pain or are not grappling at all with religious or existential questions. For example, a Protestant chaplain related the following story.

I had one male patient who was fifty-nine years old. He told me that he only "believed in himself" [*jibun o shinjiru*]. However, he respected that I was a Christian and enjoyed my coming to visit him. He never indicated in any way that he was personally interested in Christianity. But as his sickness proceeded, I heard from his wife that one time he was sleeping in his bed when he raised his arms up, saying, "I'm sinking, I'm sinking!" When I heard this, I think that even he must have reached his limit [*genkai*]; he realized that he couldn't help himself in the end. I would often share with him quotes from Hoshino Tomihiro's books and Bible verses to encourage him.<sup>30</sup> After he passed away, his wife showed me his journal that he kept by his pillow. He had recorded the quotes from Hoshino as well as some Bible verses. You can never tell what lies in a patient's *kokoro*.

When I asked another Catholic chaplain what she thought of patients who said that it was pointless to dwell on unanswerable existential questions since they "cannot be helped," she told me that these were simply excuses. "It may also mean that they don't feel comfortable talking about it with you or whomever. When a patient says that 'it can't be helped,' I ask that person, 'Why can't it be helped?' These phrases are just a way to distract oneself." This last comment hinted at the tension hospice workers must navigate between taking the expression "it can't be helped" at face value, or as indicative of the patient's reluctance to confront some real fear. One chaplain also suggested to me that part of the reason that patients are reluctant to talk about spiritual pain was because they feel that posing difficult questions that have no easy answers would actually make them a burden on those who are listening. It was already deeply upsetting for patients to allow others to change or bathe them. To broach larger religious or existential questions to a chaplain or nurse could potentially add to their fear that they were becoming a burden.

## MAKING SENSE OF SPIRITUAL PAIN

This apparent contradiction between the low number of Japanese hospice patients who openly raise “spiritual” questions and the conviction of many hospice workers and nearly all chaplains that most patients are in need of spiritual care can be interpreted in two ways. On one hand, a hermeneutics of suspicion would suggest that the clinical label of “spiritual pain” serves the needs of hospice workers, and chaplains in particular, just as much as the needs of patients. For instance, the belief that every patient has some sort of spiritual pain offers an important way for chaplains to find value in their work and legitimize their profession to medical workers who may be reluctant to refer a patient to a chaplain or to even hire a chaplain to begin with. By framing even mundane concerns as potential signs of spiritual pain, chaplains are able to employ what Wendy Cadge calls a “strategically vague frame,” that brings a broad range of patient concerns under the purview of spiritual care.<sup>31</sup> Although many chaplains recognize the arbitrariness of labels like “spiritual pain,” or have serious misgivings about the ways in which the concerns of patients are turned into a medical symptom, without the legitimization that the medical profession confers on their work, religious chaplains would be without a job.

On the other hand, a more charitable interpretation would be that the intuitions of chaplains are sometimes correct—that spiritual pain could be manifested or lie latent in ways that cursory clinical observation will miss. As one chaplain suggested, sometimes you need to “dig” for spiritual pain. This can be a delicate task and chaplains are not naïve about the risk of going about this in an untactful way or of overanalyzing the words and behavior of patients. In the eyes of chaplains who are committed to the practice of spiritual care, spiritual pain in the Japanese hospice represents a very amorphous dimension of the patient’s dying experience that eludes the clinical gaze. This is also why chaplains sometimes flag the broader relational concerns patients have about being a burden on their families as marking the presence of a hidden form of spiritual pain. Because the term “spiritual” functions in Japanese hospice care as a floating signifier, it is available for the doctors, nurses, and chaplains who are committed to spiritual care to draw on to help make sense of and respond to any number of mundane or deep existential concerns that patients may express. Although patients would never put their own experiences in these terms, caregivers fall back on the label of spiritual pain as shorthand to point to something they believe lies beneath the surface of their everyday interactions with patients. Those who are committed to the practice of spiritual care believe that the spiritual pain is not something that patients will naturally bring up with their doctor, like back pain, but is something that is often latent, subconscious, or even repressed. Since there is no single universal “sign” of spiritual pain, “sign-ification” is difficult. Instead, the symptom of spiritual pain first appears by way of entering those words into the patient’s medical chart.

“HOLDING ON TO SOMETHING”

Although the majority of dying patients are not preoccupied with religious questions or a search for something transcendent, a small number do sometimes look beyond their own lives for something to “hold on to” at the end. While few, these examples serve as an important motivator for spiritual caregivers, many who feel that true spiritual care needs to be “vertical,” connecting the patient to something transcendent, as well as “horizontal,” which connects patients to those around them.<sup>32</sup> Hara-san, for example, recognized the potential benefit of having something to hold on to, but he characterized religion as something for persons with a “weak *kokoro*” and was instead focused on fulfilling his familial obligations:

BENEDICT: Some patients go through many difficulties when they become ill. For example, their body is in pain, their movements become heavy, and there are many emotional trials. At such times, some turn to religion, or seek to rely on some sort of words or thought . . .

HARA: I understand.

BENEDICT: Yes, they seek something to hold on to. How about you? Do you have something?

HARA: Not at all. You see certain people—if I say their *kokoro* is weak, maybe this is not the right word—want to hold onto something. I think that humans are weak animals. And those with weak dispositions, they want to hold onto something [*nanika ni sugaru*]. So, for example, if it was Christianity, I think some people follow God’s teachings and keep peace in their *kokoro*. And you see, in Japan, there were many wars during the Warring States Period, and, well, as you know, as these went on, the people who experienced those tough times became convinced that there would be no happiness in this life. So, they prayed for happiness in the next life and put their whole trust in Amida Buddha and others. By doing this, their *kokoro* was saved. When there is something to hold on to, I think people are saved through the *kokoro*. But I’ve never had any feeling like this. More than that, I was [determined] to fulfill my duties somehow or another! [*Laughter.*] This was more important!

Hara-san’s view was similar to those expressed by Higashimoto-san, another patient who identified himself as nonreligious. In his mid-fifties with stomach cancer, he was mostly relieved to have his pain under control in the hospice after he developed bedsores during a stay at a different hospital. Like Hara-san, Higashimoto-san also described how he felt responsible for taking care of his affairs and the relief he felt as he finally began to tie up loose ends. When I asked if he found any support in religion, he answered:

HIGASHIMOTO: Not particularly. However, when you reach this point, I think you begin wanting to hold onto something [*sugaritai mono ga dete kuru*]. I’m in this [relatively good] condition, but there may come a time when I will express this. Perhaps you are reminded of these

things [turning to religion] depending on your condition. Well . . . you can see the talismans over there [gestures to the wall]. These are from people who are being sensitive to my condition [*ki o tsu-kawasete itadaite iru*]. If I had to say something, I might say this is religious . . . the way everyone is being sensitive to my condition.

BENEDICT: You don't have any particular religion?

HIGASHIMOTO: No, I think I'm a typical [nonreligious] Japanese. Well, I like to think that I understand different opinions better than the average Japanese, and I'm familiar with [the religious affiliation of] our household.

As Higashimoto-san explained, it was certainly possible that he might find himself supported by religious beliefs, or be reminded of it, when his illness took a bad turn; but in his relatively painless state, he did not consider it of great importance. Even the talismans hanging on the wall that he had received from various friends were explained as cultural expressions of concern. Like many Japanese, he was vaguely aware of what branch of Buddhism his family was affiliated with, but nothing more. He felt good. Unbeknownst to either of us at the time, he would pass away the next day.

In terms of religious identity, we could say that both Hara-san and Higashimoto-san displayed a kind of "cultural secularism," a form of religious subjectivity in which "religious and spiritual beliefs and practices are seen as part of and directed toward social life" and where religious participation and practice is not based on a distinct religious identity but "is subsumed within broader public morality."<sup>33</sup> For instance, Hara-san had made arrangements to be buried at an eternal memorial grave where he could be assured of perpetual memorialization without imposing a burden on his single daughter. Likewise, the healing talismans that Higashimoto-san had received from friends were objects with a religious valence, but he mostly viewed them as symbols of friendly concern for his condition.

*Yokoyama-san: "I like to chant when I go into the MRI machine"*

For some patients, however, religion did provide something they could more explicitly "hold on to" as they faced the end of life. Yokoyama-san, for example, was a patient in her late fifties who had been fighting cancer for more than a decade. Multiple anticancer treatments had taken their toll. Upon entering her room, I noticed her head was covered with a wrap, and her skin tone had darkened considerably. She was quite gaunt and spoke in a raspy voice due to being intubated. She declined to be audio-recorded, and I gathered that she was self-conscious about her voice. We talked for a little bit about her journey to the hospice. She repeated what almost all the patients said about how she did not want to be a burden on her family or cause worry for her neighbors. Her family meant a lot to her.

When I asked Yokoyama-san if she ever drew support from religion, she reached for a notebook by her bed and showed me the first page. Near the top

she had written in large characters: *nichi nichi kore kōnichi*, a saying by the Chinese Zen master Yunmen (864–949), meaning, “Every day is a good day [from an enlightened perspective].” She explained: “I look at these words in my notebook and say to myself, ‘Today is good. Tomorrow is good. Be grateful for the now.’” She also explained that she considered Fudō Myōō (Skt. Ācālā) to be her guardian deity (*mamori kami*). She admitted that while others typically look to Amida Buddha or other heavenly personages for protection, she personally preferred Fudō Myōō. She explained that this began about a decade prior when she was going through a particularly hard time and began reciting some mantras for encouragement. “I like to chant these when I enter the MRI machine. Going into the MRI is like going into your grave. The old ones anyway were dark inside, although some of the new ones have lights.” In this way, Yokoyama-san indicated that she drew some support from religion as she dealt with the daily challenges she faced in her battle with cancer. These included contemplating Zen sayings and reciting mantras associated with her guardian deity when entering the MRI machine.

*Ogawa-san: “I decided to go to the place of Jesus”*

An even more striking example of a patient who began to hold on to religion at the end of life was Ogawa-san. She was in her early seventies and was very chirpy as I came into her room. I quickly found out why—she was getting baptized that very afternoon. She showed me the small cross she was wearing around her neck that she had purchased the day before in honor of this occasion. She had received special permission from her doctor to take a trip to a store to purchase this special symbol. As we began the interview, she began talking in an excited manner about her decision to get baptized. She explained that before entering the hospice, she was a typical Japanese with no strong religious affiliation.

OGAWA: I was okay with god(s) [*kami-sama*], I was okay with Buddha [*hotoke-sama*], and I was okay with Christ [*kirisuto-sama*]. It really depended on the occasion. When I got sick and met the chaplain, I decided to choose just one. That is all there is to it.

BENEDICT: Were you not particularly religious before?

OGAWA: I had nothing. I was just playing around. I would say things like “if God existed, I should have met him by now,” or “I’ve never seen him.”

BENEDICT: But you didn’t have any aversion to Buddhism or Christianity in the past?

OGAWA: After all, when you die, you are Buddhist, right? During New Years, you go to a Shinto shrine, to the gods, right? And when you get married, a [Christian] chapel is fashionable and convenient, right?<sup>24</sup>

BENEDICT: You are very Japanese . . .

OGAWA: Aren’t I! Those who don’t hold any faith might actually have the most peace. They don’t have disputes like religious wars.

BENEDICT: Did you decide to become a Christian after you got sick?

OGAWA: My son works here. He helped me get to know the doctors and chaplains; I tend to fall into these things.

BENEDICT: What made you decide to get baptized? Was it through talking with the chaplains? Or was it by your own request?

OGAWA: They [the chaplains?] listen to me, and everyone is so kind. You know that Buddhism has the six realms [in the afterlife], and the hells and hungry ghosts are a little frightening. I wasn't always a good person [*laughs*]. I've been cruel to others and rebellious in my life. I'm frightened of going to these places. So, I decided to go to the place of Jesus. That is all there is to it. They say he accepts everyone. Isn't that nice . . . I can go without any cares.

BENEDICT: Did you have anxiety [*fuan*] before this?

OGAWA: No, I didn't. I never really got depressed. It was more like "Oh, well" [in regard to my illness] [*na'chatta mitaina*].

BENEDICT: But you were anxious about where you would go after you died?

OGAWA: Yes. After all, some Buddhist temples have paintings on the ceilings. Very frightening pictures like the hungry ghost realm. Those are unpleasant, don't you think? In the end, I want to go somewhere without them. I'm going to a place that welcomes everyone.

We then talked a little bit about her family. She had encouraged her son to also become a Christian, but he politely declined. He told her he wasn't that type.

BENEDICT: What do you talk about with the chaplain?

OGAWA: We talk about Christianity, like why he [Jesus] was put on the cross. I've only seen the film *Ben-Hur*. That is about all I know. But I'm glad I saw that. The parts where he is carrying the cross and talking on the hill made a deep impression on me.

As Ogawa-san pointed out, before she entered the hospice, she was a "typical Japanese" who occasionally participated in various forms of Buddhist, Shinto, and even Christian religious practices and ceremonies but without any strong sense of a single religious identity. However, as she reached the end of life, she became concerned over whether she would end up in one of the hell realms described in Buddhism. The Buddhist paintings she had seen had made a strong impression on her. During a subsequent visit, she handed me two and a half carefully handwritten pages that described in detail the cycle of samsara and the six paths of rebirth. At the end of her notes she wrote:

The world is eternally nonexistent [*mu*] beyond death. There is no conception of time. Time is simply a convention for those who are living. The world is as before birth. Because the brain = soul [*tamashii*] will die, it is a nonexistent world. Instead of denying death, one should be thankful for the miracle of living in this world for seventy-two years.

Although most of her notes seemed to have been culled from the Internet or some other source, it seemed that the final few lines (which included her own age) represented her own thoughts. It was also slightly perplexing, since the emphasis on “nonexistence” (*mu*) stood in contrast with her stated desire to “go to the place of Jesus.”

Ogawa-san was a classic example of a hospice patient desiring to “hold on to something” at the end of life. For Ogawa-san, the unpleasant thoughts of ending up in a Buddhist hell followed by an encounter with a Christian chaplain helped convince her to “choose just one” religion and become a Christian. Even though her knowledge of Christianity was limited to the scene of Christ carrying the cross in the 1959 classic film *Ben-Hur*, she was committed to being baptized and even tried to urge her son to become a Christian as well.

*Mizuno-san: “I am happy with the now”*

Mizuno-san was another patient who drew support from religious belief at the end of life—in his case, from Catholicism. He was in his mid-forties and in the very last stage of his battle with esophageal cancer. I met him at a Catholic hospice in Kyūshū where I spoke with him over two weeks of fieldwork on a near-daily basis. Unlike Ogawa-san, his faith predated his entrance to the hospice. However, his interest in questions about religious faith seemed to have intensified after entering the hospice. Whenever the chaplain visited him, he plied her with questions. “Should a Christian attend mass even if he dislikes the priest?” This was an issue he was debating with an online friend (in his view, one should, but only if he could attend without any malice in his heart). On another occasion, he asked the chaplain what his heavenly body might look like and if the experience would be like a caterpillar turning into a butterfly. In yet another conversation, he lighted on the topic of prayer. He explained to me that in his view Catholics seemed to use silence in prayer much more effectively than Protestants, who mostly want to talk. He explained to me, “It’s good to talk, but the primary purpose of prayer is to listen.”

Mizuno-san also had a bit of a chip on his shoulder. He particularly liked to criticize how Japanese society only valued men with successful careers. In his youth, he had dreamed of becoming an astronaut, and had studied physics at a well-known public university. His future career looked bright until he was diagnosed with mild schizophrenia. When he became unable to hold down a job due to his illness, he was forced to start living on social welfare. While receiving psychiatric treatment for his illness, Mizuno-san was told by the doctor that he “had a weak ego.” Mizuno-san explained to the chaplain that he now viewed this as a blessing. “Perhaps if my illness led me to develop a weak ego, it would be a disservice if I were healed!”

Mizuno-san’s efforts to see the silver lining in his struggle with mental illness also extended to his views on death. When he was first informed of his cancer, he said that he was not all that surprised. He even told his parents that he was looking forward to meeting God. Naturally, his parents were upset when they heard this

and asked him who was more important: God or his parents? He replied, "God. . . . Even if I could trade places with a healthy person, I wouldn't." Even getting married and having a career no longer appealed to him. "I am happy with the now," he explained. However, there had been just one time when he felt overwhelmed with a fear of death. It happened when he realized that after he died, he would no longer be able to correct anything said about him. He feared that as he would only exist in the memory of those who knew him, it was likely that others might misrepresent him. This thought scared him for a while, but "I got over it," he said.

For Mizuno-san, his Christian faith helped him deal with the disappointment of dying early in life. Death was his chance to "meet God." His positive outlook was all the more remarkable since his sentences were often punctuated by severe coughing fits. On most nights, this also prevented him from getting any sleep. Despite being in constant pain and having missed his chance to lead a normal life, he insisted that he was "happy with the now." He refused to say that if he could miraculously exchange his body with a healthier one, he would do it. His faith also played a role in how he made sense of his struggle with schizophrenia earlier in life. As he pointed out, his weak ego could be a blessing that drew him closer to God. At the same time, he seemed very sensitive about what others thought of him. For example, one of his primary fears in facing death was not being able to correct others' misconceptions about him after he was gone.

During his stay in the hospice, the question of whether Mizuno-san was repressing a real fear of death became a frequent topic of discussion amongst hospice staff. Shortly after I was introduced to Mizuno-san, his doctor came to speak with the chaplain. The chaplain personally felt that Mizuno-san seemed to be fairly accepting of his death, but the doctor thought differently. In the doctor's view, whenever he explained to Mizuno-san how his condition was changing, he seemed to grow anxious. The chaplain (who was also a former nurse) encouraged the doctor to ask Mizuno-san directly about this and see what kind of answer he received. After the doctor left, the chaplain explained to me that since most normal people are afraid of death, one could assume that Mizuno-san was, too. However, "There might be one black cow in the herd, and so you have to be aware of that and respect the uniqueness of every patient."

Patients like Ogawa-san, who underwent a deathbed baptism, or like Mizuno-san, who drew on a religious tradition for support, are relatively few. Nonetheless, the belief that some patients may find relief by holding on to something at the end is one of the key reasons proponents of spiritual care insist that a religiously trained chaplain should be part of the hospice team. A veteran Catholic chaplain explained it this way:

I think spiritual care can be divided into two levels. One level is shallower, and the other is deeper. The shallow level is spiritual care that all the staff can do. The deeper level addresses questions that only the chaplain is equipped to deal with. For example, when a patient feels "isolated," there are two levels. Sometimes it just means they are lonely and need someone to sit with them. This is the shallow kind of spiritual



care that anybody can provide. Other times, patients feel lonely even when people are with them. This is the loneliness of having to face death alone. This requires the reassurance of a God who can accompany you in life and beyond death. Or maybe a patient might ask: "Why did I get cancer?" Sometimes they just want someone to empathize with them. Other times, they may want to know what God desires them to do in this situation; helping them to address this is a deeper spiritual care.<sup>35</sup>

The chaplain added that although most patients (she estimated 80%) are only seeking the "shallower" form of spiritual care, she felt that her training as a chaplain required her to make herself available to the remaining patients who were looking for something deeper. Such patients represented opportunities for chaplains to draw on their own religious training and identity in providing care.

Of course, descriptions of "shallow" and "deep" forms of spiritual care are loaded terms. From this Christian chaplain's perspective, any kind of care that fell short of helping the patient experience God's eternal love and reassurance in the face of death was necessarily "shallow" and temporary in its effects. This positive portrayal of patients who sought to "hold on to something" provided an important justification for the work of chaplains in the hospice. While such patients may be few and far between, when a hospice patient expresses an interest in something that will help them transcend their anxieties in the face of death, the presence of a religious professional who is trained to speak on such matters can be a welcome presence, both to the patient and other hospice staff who may feel unprepared to care for such patients. These patients not only serve to legitimize hospital chaplaincy as a profession but also function as personal motivators for chaplains. During my interviews I often asked chaplains to describe a memorable past patient. Almost without fail, the patients in the cases they recounted had found something larger to seize hold of that allowed them to transcend death in some way. Books on spiritual care published by chaplains are also full of such examples and these case studies are frequently presented at conferences and in public lectures. Chaplains refer again and again to such cases of patients who do in fact express a wish to have—or gratitude for having—something to hold on to at the end. For chaplains and other hospice workers engaged in spiritual care, the presence of such patients, few though they may be, serves to reinforce their claims that a far greater number of dying patients may either be repressing or otherwise lack the courage to bring spiritual anxieties into the open.

## CONCLUSION

Clinical conceptions of spiritual pain in Japan are marked by a tension between the seeming lack of religious and existential anxiety voiced by dying patients and the insistence by chaplains and other hospice staff that all patients still feel some kind of spiritual pain to some degree. From a cynical perspective, the apparent contradiction can be explained by over-earnestness on the part of hospice workers who are invested in the concept of spiritual pain. However, a more charitable

-interpretation also shows how the anxieties of Japanese hospice patients may sometimes be manifested in subtle or deeper ways that elide clinical diagnosis. One Buddhist chaplain, for example, was very self-conscious of how his work was often portrayed with a clinical gaze that failed to account for, and fell far short of, the actual richness of the patient's dying experience:

Whether it be spirituality, spiritual care, or spiritual pain, I feel like there is an objectification [*taishōka*] that is occurring and that this approach is emblematic of one-way thinking . . . At the point when it [spirituality, etc.] becomes something controlling, or something to be controlled, rather than something that emerges in a relationship, this approach itself becomes an obstacle to deep understanding. When you say, "It should be this," at the point where you say "this," intentionality comes into play and things become arbitrary. When this happens, this aspect of control and something to be controlled surfaces, and you lose what was originally a very rich thing. It becomes too narrow or even trivialized. I think these [concepts] refer to something that is essentially very rich, thick, and deep. While these concepts provide us an opportunity to help us touch on these things, I think there is a danger to saying, "It's this!" since this will overlook all kinds of things. So, my own image of spirituality is very rich, and at the point where you turn it into "something," I feel like it is becoming trivialized.<sup>36</sup>

This chaplain felt that as helpful as the concept of spiritual pain was in legitimizing his profession, there was also a danger of applying this concept too widely and trivializing the deeper anxieties that patients might be facing at the end of life.

This mismatch between the label of spiritual pain and the actual concerns voiced by patients is significant for several reasons. First, we must recall that most Japanese patients have no idea what the term "spiritual pain" really means, or why the chaplain is even there. Thus, from the patient's perspective, spiritual pain remains an empty or amorphous concept. Second, most Japanese hospice patients describe themselves as not religious and only rarely raise questions about a search for religious meaning or belief in something transcendent at the end of life. This calls into question of traditional definitions of spiritual pain that are focused on a "search for meaning." Although some patients may occasionally express anxiety or concerns about guilt, meaning, the afterlife, or their relationship to some transcendent power, many more either appear unconcerned, or, at least, tend to deflect such questions; instead, they voice their concerns about social relationships, being a burden on others, and their unfinished duties toward family and friends. Third, the practice of sharing personal dilemmas with chaplains—let alone deep existential questions—remains culturally incongruous for many, particularly elderly Japanese patients. As a result, even when a chaplain has reason to believe a patient has spiritual pain, it can be difficult to address it directly. Instead, spiritual caregivers attempt to support the patient and focus on allowing that person to spend his or her last days in a way that they believe will allow the patient to "be himself" or "be herself" until the end.

None of these findings are to deny the utility of spiritual pain as a valuable tool in clinical settings. The challenges that Japanese chaplains face in legitimizing their profession or even just making it comprehensible to their fellow medical workers, who are steeped in biomedical frames of reference, make the concept of spiritual pain critical for practicing spiritual care at the end of life. Moreover, those few patients who do seek out something to “hold on to” give chaplains and other proponents of spiritual care reason to believe that there are patients who have deep existential needs that fall outside the purview of clinical psychology. In the meantime, as shown in previous chapters, chaplains and other hospice staff focus on meeting the more prosaic needs of patients. In addition to sitting and listening to patients, the work of chaplains also consists of “supportive care,” which includes interacting with patients through tea gatherings, gardening, walks, concerts, birthday parties, seasonal festivities, and impromptu movie screenings, all conducted with the goal of helping patients to be themselves. If Nakano Kōji, who was introduced at the very beginning of this chapter, had entered hospice care, no doubt arrangements would have quickly been made to ensure that he could walk his dogs. This speaks to a more embodied understanding of spiritual pain and spiritual care that does not seek to distinguish between the physical, social, psychological, and spiritual dimensions of a patient’s total pain. Rather, the search for spiritual pain ends by noticing that, ultimately, the deepest concerns of hospice patients are entangled in a dynamic bricolage of daily routines, social relationships, psychological pressures—and in some cases, religious beliefs—that are inextricable from what we normally just call life.