The Lack of Spirituality in End of Life Care in Japan

Masako Nagase

Faculty of Nursing and Health Care, Juntendo University, 2-5-1, Takasu, Urayasu, 279-0023, Chiba, Japan
*Corresponding Author: mnagase@juntendo.ac.jp

Abstract As the modern hospice movement developed in divergent directions, early principles relating to spirituality changed as the movement entered Japan. How did this development occur? This paper seeks to answer this question by examining changing notions of spirituality in UK/US and Japan during the development of the hospice movement. The history of the hospice movement is divided into four temporal/chronological stages: A. development of the hospice movement in the UK and US; B. the institutionalisation of the hospice movement in the UK/US; C. development of the Japanese hospice movement; and D. the institutionalisation of the hospice movement in Japan. Attitudes towards and policies regarding spirituality during each of these stages is examined in detail, along with associated approaches to diagnosing, disclosing, and accepting death. I argue that in Japan, the processes of standardisation and institutionalisation of hospice care have resulted in the loss of spirituality as its organizing principle.

Keywords Spirituality, Spiritual Care, Modern Hospice Movement, Palliative Care, Japan

1. Introduction: Development of the Modern Hospice Movement

It was not until the start of the modern hospice movement that many healthcare professionals began to recognise caring for the terminally ill as an important role in modern medicine. An important part of the movement was the belief that medicine should encompass more than treating patients merely by using the latest medical technology.

One of the main factors contributing to the development of the modern hospice movement was the institutionalisation and incorporation of hospice care into national healthcare policy, as demonstrated by developments in the UK. Until 1965, the UK had no more than 15 hospices. There was no significant upward trend for the following decade, but in 1975, the number of hospices began to grow sharply. By 1991, there were at least 430 (Field, 1994; James & Field, 1992). The first wave of hospices in the UK had been independently managed and dependent on the support of charitable organisations. As a result, they began to run into financial difficulties in the 1980s. In order to secure the funding necessary to provide and manage hospice care sustainably, they had to be incorporated into the medical system under the jurisdiction of the National Health Service. Moves were also made to incorporate hospice care into mainstream medicine in the 1980s, with the establishment of end of life care as a minor subject in the medical school curricula of state-run institutions (James & Field, 1992). This move may have contributed to the development of the modern hospice movement.

The hospice movement itself was pioneered by Cicely Saunders in the UK and Elisabeth Kübler-Ross in the US, and was introduced into Japan by Tetsuo Kashiwagi, Fumio Yamazaki, and others during the 1970s (though it was not, as mentioned above, fully incorporated until the 1980s). Saunders believed that a hospice should function as a medical setting, a religious institution, and a community as an extension of the family (Du Boulay, 1984). She argued that the pain caused by cancer consisted of four dimensions: physical, emotional, social, and spiritual. She referred to this concept as total pain, stressing the need to care for the ‘whole person’ (Saunders & Baines, 1989). Saunders argued that end of life care needed to treat physical symptoms such as physical pain and discomfort, but also to address spirituality (Du Boulay, 1984). She founded St Christopher’s Hospice in 1967 based on these principles, and her ideas were disseminated throughout the world by the many doctors and nurses who underwent training there.

Kübler-Ross was critical of the state of end of life care during the 1960s. She believed that because doctors were withholding diagnoses and prognoses, patients were not able to come to terms with the reality of their imminent death. She argued that the concealment of terminal diagnoses coupled with the denial of death in society was leading people to lose hope and purpose in their life. In particular, in the days before the advancement of science and technology, she pointed out that there had also been a denial of death in religion—in the sense that there was a belief in life after death (arising from the belief in the immortality of the soul). However, this belief in a life after death enabled people to understand and find meaning in painful life experiences. As a result, they were able to continue to have hope and find a purpose in their lives even when confronted with the reality of impending death (Kübler-Ross, 1969).
Kübler-Ross (1969) argued that in order for people nearing the end of their lives to be able to accept and find peace in their death, they need to be able to face up to their reality on a personal level. An important part of end of life care, therefore, is for doctors to inform terminally ill patients of their diagnosis and prognosis, and provide the necessary support—which would include the spiritual dimension—to enable them to accept their imminent death. However, she denied the existence of spirituality in the sense of the soul continuing to live on after the body dies. She was a psychiatrist, and she emphasised the importance of using psychotherapeutic methods to help people at the end their life to accept their impending death emotionally (Kübler-Ross, 1969). This approach contrasts with that of Saunders, who promoted spirituality—in the sense of the eternal soul—as a dimension of end of life care.

As hospice care became institutionalised and incorporated into mainstream medicine, however, the Saunders’ ideas and philosophy seem to have been lost. Hospice care was even said to have undergone routinisation (Bradshaw, 1996; James & Field, 1992). The modern hospice movement sought to change end of life care and often even mainstream medical systems (James & Field, 1992); nonetheless, in this regard, it cannot really be considered as successful.

It was not just in the UK that the institutionalisation of hospice care took place, but also on a global level. In 1989 and 1990, the WHO Regional Office for Europe and the WHO Expert Committee, respectively, published booklets setting out international guidelines relating to palliative care. They aimed to standardise palliative treatment as well as maintain and improve the quality of palliative care.

1.1. Origins and development of the hospice movement in Japan

Tetsuo Kashiwagi began to provide hospice care within a hospital setting in 1973, which marked the beginning of hospice care in Japan. It was initially structured as a team activity rather than as a hospital ward, but after undergoing training at Saunders’ St Christopher’s Hospice in 1979, Kashiwagi set up a hospice ward in 1984. Japan’s first independent hospice ward had been set up in another hospital (Seirei Mikatahara General Hospital) in 1981, and the first national palliative care ward was opened in 1987.

Concurrent to these developments with hospice, in the late 1970s and the early 1980s, private organisations in Japan were also discussing and thinking about how death is dealt with in society. These groups were composed of ordinary citizens in addition to researchers and policymakers. Fumio Yamazaki, Japan’s leading hospice physician and researcher, became interested in end of life care shortly after Kashiwagi did. In 1983, he spent a year working as a ship’s doctor, and it was during this time that he read Kübler-Ross’s On Death and Dying. Inspired by her ideas and back on dry land working as a hospital doctor, he went on to organise a end of life care research group and continued to study issues regarding life-prolonging treatment in end-stage cancer patients and diagnosis disclosure, as well as hospices. In 1990, he published his first book, Byōin de Shinu toukotō (Dying in Hospital). It became a best-seller in Japan and was even made into a film. The book discussed what prompted his involvement in the hospice movement as well as his ideas surrounding end of life care. It also had an impact on people outside of the medical field.

The Japanese hospice movement entered the institutionalisation stage in the late 1980s, starting with efforts at the national level to improve the quality of end of life care through standardisation attempts. In 1987, a model project was implemented to establish end of life care as a medical speciality in mainstream medicine in Japan. Thus, in 1990, the health insurance system recognized ‘[i]n-patient hospitalisation fees for palliative care’ as a new category of medical fee eligible for compensation. The hospices that existed at this time had been set up by people who sympathised with or had been inspired by the principles of modern hospices and wanted to put them into practice. In 1990, they were registered by the former Ministry of Health & Welfare as ‘palliative care units’, and their numbers increased over the following years.

Thus, in the 1990s, in addition to the standardisation and assessment of hospices and palliative care, academic institutes were set up to promote interdisciplinary and scientific research. Though Japan was several years behind the UK, palliative care at that time could be legitimately regarded as a medical speciality. From 2000 onwards, discussions have been ongoing within the Ministry of Health, Labour and Welfare concerning guidelines relating to the kind of care that should be provided to people nearing the end of life.

1.2. Changing notions of spirituality in the modern hospice movement

A good death has four ‘cultural scripts’, ways to die well: modern medicine, revivalism, an anti-revivalist script, and a religious script. These scripts can also be found in Japan and in anglophone countries (Long, 2004).

In this paper, in the early years of the modern hospice movement, some believed that end of life care should include spiritual care, whereas others saw the aim of terminal care as enabling patients to come to terms with their own death and did not recognise spirituality (in the sense of an afterlife or eternal soul) as part of this. Regardless of their stance, proponents of the movement sought to identify the problems with end of life care and set out to provide a new kind of hospice care, drawing a clear line between hospice care and ordinary medical care. As the movement developed, hospice care was integrated into ordinary medical care, moves were made to standardise and institutionalise it, and the movement spread to other countries outside of the UK/US as well.

As the modern hospice movement developed in these divergent directions, the early principles relating to spirituality changed as the movement entered Japan. How did this development happen? This paper seeks to answer
2. The Positioning of Spirituality in the Modern Hospice Movement

Four stages of the modern hospice movement. The process whereby the modern hospice movement developed can be considered to comprise four stages. It developed in two directions: from a movement towards institutionalisation and from the UK/US towards Japan. These works, authored by people, organisations, or committees that are representative of each stage, are used to examine how spirituality was treated during each of the four stages, how issues of diagnosis disclosure and accepting death were dealt with, and, through cross-comparison, how the movement changed at each individual stage.

Saunders’ and Kübler-Ross’s books are used as the representative works for stage A, which concerns the hospice movement in the UK/US. Saunders jointly authored Living with Dying with Mary Baines in 1983, and Kübler-Ross published On Death and Dying in 1969. vii

The representative documents used for the institutionalisation of the hospice movement in the UK/US (stage B) are the sets of palliative care guidelines produced by the WHO Regional Office for Europe and a WHO Expert Committee: viii Palliative Cancer Care – Policy Statement Based on the Recommendations of a WHO Consultation from 1989 and Cancer Pain Relief & Palliative Care - Report of a WHO Expert Committee from 1990. The policy set out in Cancer Pain Relief & Palliative Care is said to be based on the results of the approaches to symptom control implemented at Saunders’ St Christopher’s Hospice.

The books published by Kashiwagi and Yamazaki are employed for stage C, the spread of the hospice movement to Japan. The influence of Saunders and Kübler-Ross was instrumental in efforts to implement hospice care in Japan. The works used are Kashiwagi’s 1983 Sei to Shi wo Sasae ru – Hosupisu Kea no Jissen (Supporting Life and Death: The Practice of Hospice Care), as well as his 1986 work, Shi ni Yuku Kanja to Kazoku he no Enjo – Hosupisu Kea no Jissai (End-of-life Support for Patients and Their Families: The Reality of Hospice Care) (Kashiwagi, T., 1983; Kashiwagi, T., 1986).ix Referred to also is Yamazaki’s book published in 1990, Byōin de Shinu toiukoto (Dying in Hospital). x In Japan, there were many home hospice physicians since 1960’s, who published their work or established an association. I guess that they had influenced Kashiwagi and Yamazaki. And yet, the reason for choosing Kashiwagi and Yamazaki is that there were their own copyrighted works for the general Japanese, that the effects of them were great, and that it is easily available even now their literature.

To represent stage D, the institutionalisation of hospice care in Japan, I refer to the care manual for last-stage cancer patients that was produced in 1989 by an investigative commission, set up by the former Ministry of Health & Welfare, to look into the state of end-of-life care (Japan Medical Association, Ministry of Health & Welfare, 1989), as well as the same ministry’s memorandum concerning the 1990 revision of points allocated to medical fees covered by the state health insurance programme.

It appears that spirituality within end of life care is positioned differently in each of the four stages (see Table 1). With the exception of Kübler-Ross’s work, spirituality was seen as a dimension of end of life care in the UK/US at both stage A—in the hospice movement—and stage B—during its institutionalisation. In Japan, on the other hand, spirituality (in the sense of the world of the dead) was not recognised as a dimension of end of life care at either stage C—when the hospice movement arrived in Japan—or stage D—during its institutionalisation. With regard to the positioning of end of life care, at stages A and C, it was positioned as an entity separate from common medicine, while at stages B and D, it was positioned as a medical speciality within mainstream medicine.

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<th>Stage</th>
<th>UK/US</th>
<th>Japan</th>
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<tr>
<td>Stage A</td>
<td>Spirituality – in the broad and narrow sense – is an important dimension of care. The end of life care setting is an extension of the family; it is different to ordinary medicine.</td>
<td>Spirituality rarely features as an important dimension of care.</td>
</tr>
<tr>
<td>Stage B</td>
<td>Spirituality is a dimension of QOL – the central concept of end of life care. End of life care is a special field within ordinary medicine.</td>
<td>End of life care – without spirituality – is a field of ordinary medicine.</td>
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<tr>
<td>Stage C</td>
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<td>Stage D</td>
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At stage A, Saunders believed that medical control was possible for the physical symptoms presented by end-of-life patients. The physical symptom she believed to be most important was pain. She saw suffering as comprising physical, emotional, social, and spiritual dimensions, and asserted the primary importance of properly controlling physical pain. It is only when we are able to control the physical pain properly that we become aware of the other three dimensions—i.e. the ‘more subtle problems that have to be addressed’. Saunders and Baines (1989) wrote that “many patients need help to face feelings of guilt and worthlessness that can be truly described as spiritual pain, sometimes amounting to deep anguish” (p. 48). This shows that Saunders believed that the pain experienced by patients nearing the end of their lives had a spiritual dimension, and that spiritual care was necessary to address it. However, spiritual pain should be dealt with only when physical pain had been medically controlled.

Saunders also argued that end-of-life care should be about managing patients for whom imminent death is certain and fast approaching, and that the focus of medical care should shift from active treatment to controlling symptoms and supporting the patients and their families. She believed that in order for a hospice to provide this support appropriately, it needed to be not only a medical facility, but also a religious organisation and a community that was an extension of the family. This approach shows that Saunders regarded the kind of end of life care that should take place in hospices as separate from that given in an ordinary medical setting. The job of dealing with the spiritual problems faced by end-of-life patients with a faith/religion was to be undertaken by a chaplain, priest, or other religious person. If the patient was not religious, spiritual issues were to be addressed by the care provider.

Kübler-Ross (1969) on the other hand, disputed that spirituality—in the world-of-the-dead sense—would be an avenue of help for patients in accepting the reality of their impending death. She argued that before modern advances in science and technology, a form of denial of death had also existed in religion—in the sense that there was a belief in life after death (immortality). She understood that this earlier belief in a life after death enabled people to find meaning in painful life experiences and to comprehend them better. As a result, they were able to continue to have hope and to find a purpose in their lives even when confronted with the reality of their death. In modern day society, however, she argued that scientific advances had caused people to lose their unconditional faith or belief in the soul or afterlife. This loss had resulted in a greater fear of death. A spirituality of this nature, she believed, would be of no help for people in modern-day society.

At stage B, the focus of palliative care was more on quality of life than on prolonging life: ‘The most important, or rather only, aim is to increase patient comfort as much as possible’ ("Palliative care: Policy statement based on the recommendations of a WHO consultation," 1989). The relevant "Cancer pain relief & palliative care: Report of a WHO expert committee" 1990) regarded palliative care as ‘the active and whole-body medical care of patients with conditions that no longer respond to treatment aimed to cure them’, and considered that ‘the most important task is to control pain, control symptoms other than pain, and resolve emotional distress, social issues and spiritual problems’. The aim of palliative care was thus to ‘improve and maintain the quality of life of patients with incurable conditions’ ("Cancer pain relief & palliative care: Report of a WHO expert committee," 1990).

It is clear that the WHO regarded the focus of end of life care as quality of life (QOL), with improving QOL as its aim. This concept of QOL includes physical and mental health: that is, rather than simply looking at whether or not the patient is presenting with symptoms, end of life care needs to take into account such aspects as physical capacity, psychological/emotional capacity, vitality, and religion/faith/spirituality.

The WHO defines spirituality as ‘an experiential aspect relating to living as a human being and a term that expresses experience gained that transcends phenomena that are material in nature’ ("Cancer pain relief & palliative care: Report of a WHO expert committee," 1990). If a disease progresses and becomes difficult to treat, patients can begin to have doubts about the meaning and purpose of their lives. These kinds of doubts are spiritual problems, and ‘for many people, the spiritual aspect of “being alive” includes religious elements’. Therefore, in order to address spiritual matters, the care team should include an appropriately trained spiritual counsellor ("Palliative cancer care: Policy statement based on the recommendations of a WHO consultation," 1989). In sum, it is apparent that, in contrast to Saunders, whose principles centred on people with a religion, after which she considered how best to deal with people without a religion, the WHO first of all deemed spirituality to be inherent to being human—in the sense of having a meaning and purpose in life—and then recognised that some people have a particular religion or faith.

At stage C, Kashiwagi sees a hospice as a place for people to live out their days ‘in their own way’ (Kashiwagi, T., 1983), and writes of a place to ‘settle one’s final accounts of life’ (Kashiwagi,T., 1986). It is important for patient symptoms to be controlled in hospices, but we do not need hospices to do this. In fact, the main care that patients should receive in a hospice is the work that comes after pain control—in other words, receiving help to settle the final accounts of their life. As such, Kashiwagi positions hospice care as an entity separate from common medicine.

The terms used by Kashiwagi—‘living their own way’ and ‘the final accounts of life’—emphasise the nature of human life in its final stages. Because life is completed through death, the aim of hospice care is to help patients to live their final days in their own way. Kashiwagi takes the approach that a patient’s religion/faith should be accepted as part of their ‘own way’. This is a different perspective from that of Saunders, who focuses on people with a religion/faith.

For Yamazaki (1990), too, a hospice is a place to live out
one’s final days ‘as a human being’ and a place of ‘mutual support’; he also sees the aim as helping patients to live in their own way. With regard to spiritual care, he believes that patients should be able to receive whatever religious support they want at a hospice, be it Christian, Buddhist, or any other religion. However, in order to make it possible to practise and expand hospice care in Japan, he argues that hospices need to provide non-denominational spiritual care.

Because it would be difficult to provide religious care at national hospitals, some facilities work with plants and animals to provide spiritual care, but Yamazaki (1990) says that this approach risks overlooking the most fundamental and essential element of end-of-life care, by which he is referring to the importance of living out one’s final days as a human being. Helping patients to be able to spend the final stages of their life ‘in their own way’ or ‘as a human being’ is the very raison d’etre of a hospice. Thus, in his belief that hospices should help patients to live in their own way, he shares the same perspective as Kashiwagi.

At the same time, (Yamazaki, 1990) says that regular cancer treatment or life-prolonging treatment would, of course, be provided if that is what the patient wants. In arguing that ‘clinging to life’ should be accepted and supported if it is the patient’s ‘own way’, we can see that Yamazaki sees ‘one’s own way’ and a ‘desirable death’ as relative concepts. In this respect, he differs from Kashiwagi.

Thus, both Kashiwagi and Yamazaki emphasise patients’ being able to live in their own way during the final stages of their lives. With regard to the question of an eternal soul and life after death, both men also adopt the stance of letting the patient determine whether such is important or not. The Japanese and the UK/US hospice movements differ little with regard to a hospice setting as a place where people can ‘die as human beings’. However, whereas Saunders attaches a great deal of weight to controlling pain and other physical symptoms as a prerequisite for end-of-life hospice care, this is not really emphasised in Japan.

At stage D, we see no mention of spiritual care in either the care manual for last-stage cancer patients or the medical fees covered by the state health insurance programme. In other words, spirituality—in the sense of both the world of the dead and the meaning of life—has been erased from end of life care.

### 2.1. Diagnosis, disclosure, and acceptance of death

Across the four stages, the approach to diagnosis, disclosure, and accepting death is largely divided into two camps (see Table 2). Stages A and B reveal a consensus that the patient’s diagnosis should, in principle, be disclosed. At stages C and D, however, the decision whether or not to disclose the diagnosis is to be determined case by case and based on a judgement about the patient’s capacity to accept the reality of the situation.

At stage A, (Saunders & Baines, 1989) writes that, ‘as long as there is no decline in the patient’s mental capacity, we must not forget that the medical contract is entered into with the actual patient’ and argues that hospice patients, who have only a few months left to live, should be told the truth. She believes that diagnoses should be disclosed even in a terminal-care setting, but that ‘advance consideration must be given to whether patients’ questions will be answered or left unanswered’. She does not mean that healthcare providers have the option of ‘not answering’ patients’ questions. Rather, she is attempting to convey that in order to make it easier for the patients to accept that they are going to die and to make it easier for them to adjust to their deteriorating health, rather than merely issuing an ‘announcement’, healthcare providers should ‘tell the truth while being prepared to take some kind of remedial action’.

Saunders says that if healthcare providers explain to dying patients, who usually do not have a clear understanding of what death involves, that they will certainly be able to control any pain and that death is a peaceful experience, this will set their minds at ease and make it easier for them to accept it. Saunders asserts that end-of-life patients welcome the opportunity to face the truth, i.e. to be informed of their diagnosis, and that care providers should try to present this opportunity. However, although she believes that a terminal diagnosis should be shared with the patient, she sees the issue of accepting death as a problem separate from spiritual pain and, as such, not the aim of end of life care.

#### Table 2. Diagnosis disclosure and accepting death in end of life care

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<th>Hospice movement</th>
<th>Institutionalisation</th>
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<tr>
<td>UK/US Stage A</td>
<td>Disclosure is a prerequisite for patients choosing to receive hospice care</td>
<td>The patient decides whether or not to receive life-prolonging treatment, and disclosure is a prerequisite for being able to make this decision.</td>
</tr>
<tr>
<td></td>
<td>All people have to come to terms with the reality of their own death</td>
<td>A spiritual counselor helps patients come to terms with their diagnosis.</td>
</tr>
<tr>
<td>UK/US Stage C</td>
<td>Patients can receive hospice care even if they have not been informed of their diagnosis.</td>
<td>Disclosure is necessary in order to prevent patients’ losing trust in their doctors.</td>
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<tr>
<td></td>
<td>Because not all patients are capable of coming to terms with their imminent death, their capacity to accept this needs to be ascertained first.</td>
<td>Before disclosing a terminal diagnosis, it is necessary to determine the patient's ability to accept it.</td>
</tr>
<tr>
<td>Japan Stage D</td>
<td>A trained counsellor helps patients come to terms with their diagnoses.</td>
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Kübler-Ross (1969) says that because end-of-life patients need to face up to and come to terms with the reality of their impending death, being informed of their diagnosis is essential. Whether or not to disclose is not the issue, but rather how it should be done and what kind of techniques should be used. She believes that whereas in the past believing in an afterlife or the world of the dead helped people to accept death, now that people have lost this kind of faith, they can be helped to accept the reality of death through psychotherapeutic care.

At stage B, a support system is advocated as a way of improving the QOL of end-of-life patients. The aim in building such a system is to help patients live as actively as possible while facing up to death—in other words, to come to terms with their impending death and live out the rest of their days ("Palliative cancer care: Policy statement based on the recommendations of a WHO consultation," 1989). The WHO Expert Committee’s stance is that the patient should be the one to decide whether to receive life-prolonging treatment (1990) or to forego such treatment in favour of palliative care.

Ascertaining the ’patient’s will’ in such a situation involves telling patients that death awaits them in the near future. The WHO Expert Committee’s booklet does not discuss in detail how one should deal with diagnosis disclosure and come to terms with death, but the fact that priority is given to the patient’s will in determining whether or not to continue life-prolonging treatment demonstrates that disclosure is considered a prerequisite for palliative care. It is argued that if the patient’s condition deteriorates and becomes difficult to treat, a specialist spiritual counsellor should support the patient in dealing with the spiritual matters that arise in coming to terms with their imminent death ("Palliative cancer care: Policy statement based on the recommendations of a WHO consultation," 1989).

At stage C, Kashiwagi, T. (1986) writes, certain conditions need to be met before a diagnosis should be disclosed to a patient. These conditions are threefold: the patient asks to know; the patient has the capacity to accept the diagnosis; the patient has a suitable support system. The people involved in providing end of life care need to determine whether the patient fulfils these criteria.

Patients would be considered able to accept a terminal diagnosis if they can perceive a sign of human existence within even the most inconvenient of circumstances and if the care provider in an ordinary clinical setting feels that they would be able to cope with a cancer diagnosis. If the patient is deemed capable of accepting the diagnosis, has a strong desire to know the truth, and is someone who characteristically tends to ‘want clear answers’, this person’s life can be supported by disclosing the truth. However, Kashiwagi adds that not all patients are capable of accepting a cancer diagnosis, and there are some patients whom it is better not to tell. Kashiwagi seems to view many Japanese people as having a low capacity for accepting a terminal diagnosis—in that he argues that not everybody can deal with the fact of their imminent death—and proposes a method for ascertaining a patient’s capacity. In this respect, his stance differs from that of Kübler-Ross.

Because Yamazaki (1990) believes that patients should be the ones to request hospice care—in full knowledge of the associated principles and reality—he sees diagnosis disclosure as a prerequisite for receiving hospice care. He describes hospices as support programs for people who express a wish to live out the rest of their days to the full in complete knowledge of the nature of the hospice system. Even if it is the family rather than the patient that has requested hospice care, he still believes that patients should be informed of the truth if they want to know. In this way, Yamazaki takes a more pro-active approach to diagnosis disclosure than does Kashiwagi.

Yamazaki (1990) also writes that to act in accordance with the patient’s will and to ensure that it is based on their true feelings, hospice patients must always be given the correct information; nonetheless, he says, it is also possible to withhold the diagnosis if the patient requests not to be told. In this, he differs from Kashiwagi, who asserts that it should be the healthcare provider who determines the patient’s ability to accept the diagnosis. However, in a hospice setting, the very act of ascertaining whether a patient wishes to be told is akin to disclosing a diagnosis; it is a logistical impossibility for a patient to receive hospice care without communicating on some level the existence of a terminal diagnosis.

In stage D, the former Ministry of Health and the Japan Medical Association (1988) adopted the following stance on disclosure: Although it may not be appropriate to treat all end-of-life patients in a uniform manner, it is highly beneficial to disclose a terminal diagnosis, and it is important that healthcare providers make every effort to inform patients after they have properly evaluated the associated advantages and disadvantages. The benefits are described as follows:

In light of the fact that disclosing a terminal diagnosis can lead patients to lose the will to live or generate a shock that could cause emotionally instability, the issue of disclosure has come to be sidestepped to a greater extent than previously. However, in order to circumvent the distrust that comes with non-disclosure and to provide better care to end-of-life patients, doctors must deal with this issue head-on, rather than avoiding it. (Ministry of Health, Japan Medical Association, 1988)

No similar assertion—that consideration should be given to whether or not to disclose a terminal diagnosis so as to prevent distrust of the medical profession—is apparent at stages A, B, or C. Deeming it best to disclose if doing otherwise would negatively affect the relationship of trust between doctor and patient is a rather doctor-centred argument.

On deciding whether to disclose, the Ministry of Health and Japan Medical Association (1988) has this to say:

When [disclosing], a range of individual conditions should be taken fully into account, such as the patient’s age, sex, personality and way of thinking, family relationships, social
standing, experience, and the patient’s wishes regarding end-of-life care. Furthermore, consideration should also be given to the way the disclosure is phrased, and the time chosen carefully. Rather than informing the patients in direct terms, another method would be to inform them indirectly, only implying the relevant diagnosis.

3. Discussion

In both the UK/US hospice movement and its subsequent institutionalisation, spirituality is positioned as a dimension of end of life care, and spiritual care is considered necessary. By contrast, in the Japanese hospice movement and its subsequent institutionalisation, spirituality is not recognised as an essential dimension of end of life care, whether in the sense of faith/religion or in relation to the meaning of life. In the Japanese hospice movement, it is considered important to help people to be able to live out the last stages of their life in their own way. Thus, it would seem that if the patient has a faith or religion, such would be regarded as one part of their own way, and they should be supported in dying in a way that fits with their beliefs. Nonetheless, in the institutionalisation of hospice care in Japan, spirituality completely was internalized. This situation is probably the result of an attempt to maintain the principle of the separation of church and state in state medical facilities.

In the hospice movements in both the UK/US and Japan, end of life care was initially positioned as associated with practices and settings that are separate from those in common medicine. Later, during the institutionalisation of hospice care in both the UK/US and Japan, end of life care came to be regarded as a medical speciality within mainstream medicine. In terms of the movement toward institutionalisation also, a kind of interaction effect can be identified between the UK/US and Japan. However, the way that spirituality is positioned within end of life care differs between the UK/US and Japan. As hospice care became institutionalised in the UK/US, the focus of end of life care was deemed to be QOL. This concept is also used in mainstream medicine, and spirituality is positioned as a dimension of it. In Japan, by contrast, spirituality has been completely erased as an important dimension of end of life care.

Approaches to diagnosis, disclosure, and acceptance of death in end of life care also differ between the UK/US and Japan. In the UK/US, when hospice care was a still movement as well as after it became institutionalised, the decision for deciding to receive hospice care rested with the patients in full knowledge of their diagnosis. It was believed that if patients were given the opportunity to face the truth, they would be able to come to terms with their reality. For this reason, it was argued that a terminal diagnosis should be disclosed. However, at the institutionalisation stage (B), coming to terms with death was not necessarily considered an actual aim of end of life care. In this regard, the assertions of Saunders at stage A appear to have been carried over.

In Japan, on the other hand, at both stages it was argued that a terminal diagnosis should be disclosed on a case-by-case basis and that patients should be entitled to receive hospice care even if they had not been informed of their diagnosis. In fact, it was considered necessary to ascertain the patients’ capacity to accept their condition before disclosing a terminal diagnosis, because it was thought that not all patients are capable of coming to terms with their imminent death. This makes us look like that patients in Japan were thought to have a lower capacity for accepting a terminal diagnosis compared with patients in the UK/US.

It has been demonstrated that the positioning of spirituality in end of life care in Japan changed substantially over the development of the modern hospice movement. In spreading from the UK/US to Japan, several aspects, including the approach to spirituality, disclosure, and accepting death, underwent change. I argue that spirituality came to be positioned differently in Japan because people in contemporary Japanese society no longer look to faith/religion as something they can fall back on, in the sense of their soul’s living on after death. Because, for the same reason, it was thought that most Japanese people find it difficult to come to terms with a terminal diagnosis and their imminent death, I argue that this also explains the change in the approach to diagnosis disclosure and accepting death. Other changes—the institutionalisation of hospice care, the inclusion of end of life care in mainstream medicine, the standardisation of care, and the routinisation of hospice care (Bradshaw, 1996; James & Field, 1992)—occurred in Japan as well as in the UK/US.

However spirituality is so important at all levels and stages of care, especially it is easy to appear in end of life. It is the rights and healing for the dying person and his family to receive the emotional and spiritual care, and it is the ethical matter and duty for the health care providers to the emotional and spiritual support.

It is said that modern hospice originated in the UK and had a major impact on the world. In the UK, Christian approach or religious approach was dominant as spiritual care to people dying (Walter, Tony, 1996). In addition, an approach to personalized modern, (the search for meaning) has been added to the spiritual care. Such an approach has been used for the following reasons: (1) to provide hospice, (2) a multi-professional approach (3) to be centred around Christianity, and (4) to professionalise of nursing based on a whole person care (Walter, Tony, 1997). In addition, in the context surrounding the post-modern era the role of the church has decreased as many patients and employers of hospice have become secular. Therefore, the approach to hospice care is not a religious one (Walter, T., 2002).

If incorporating spirituality into medical care served as something of a warning for mainstream medical systems, and if incorporating spirituality was what the modern hospice movement set out to do, then it seems to have failed in Japan, as no trace of these efforts appears to have remained. However, if we regard the period leading up to the
1990s in Japan as still a time of development and education concerning the technology for relieving physical pain in end-of-life patients, we can argue that it is inevitable that the principles of hospice care were erased during the process of its institutionalisation. That is, it is understandable that at the institutionalisation stage, guidelines have to be set out so that hospice care will be accepted by the wider population, and setting out hospice care in explicit and concrete terms may result in the loss of some of these original principles. However, with the rapid advances in medical technology in recent years, the increasing importance of ethical decision-making in medicine care has once again gained attention.

Stating that spirituality is no longer needed may not be true and this paper points out that the situation is much more complex and nuanced than it is currently. That is exactly why papers concerning the spiritual care for terminally patients are increasing in Japan, such as Tamura et al. (2006) research on the development of measures for spirituality, as well as investigations on living one’s daily life with pleasure at the end of life (Ando, Morita, Lee, & Okamoto, 2008; Nakano, Sato, Katayama, & Miyashita, 2013). And as Long (2004) said, it is surely time for healthcare providers to reconsider the role of end of life care as more than simply technology for palliative care, and to engage in deliberations and discussions on the role and nature of medicine in society today with the wider public.

REFERENCES


The differences between modern hospices and mainstream medicine have been cited as respect for the individual, avoiding excessive life-prolonging treatment, relieving pain and a range of other symptoms, and the focus on emotional care (Okuyama, 1999). These days, “hospice” is a general term used to describe programs of holistic care for patients at the end of their lives which aim to improve quality of life rather than actually cure diseases (Maruyama, 1999).

The name of this minor subject changed from ‘terminal care’ to ‘palliative medicine’ in 1987. Palliative medicine is a specialist field within hospice care that particularly deals with symptom relief and emotional care. The practice of palliative medicine is referred to as ‘palliative care’ or ‘palliative treatment’. Thus, by focusing on only the palliative care element of terminal care, we can say that a medical speciality was established.

St Christopher’s Hospice was a medical foundation as well as a religious association established as an inter-denominational Christian foundation. Its mission is to ‘provide spiritual support and guidance to everybody here (patients and non-patients alike), and to relieve pain by supporting the provision of such care or working with suffering families’. Rather than positioning hospices as medical facilities within the medical system, Saunders wanted to see them independently established as religious associations (Du Boulay, 1984).

The concept of the ‘denial of death’ first became common currency in the US with the development of the hospice movement (Zimmermann, Camilla & Rodin, 2004). According to Zimmermann, C. (2007), ‘it had always been considered natural and even functional to repress the unpleasant reality of death’, but since the late 1960s, doing so has come to be viewed negatively as essentially denying death. With the development of the hospice movement, the denial of death came to be negatively understood as preventing 1) an open discussion of death, 2) patients’ dying at home, 3) advance preparation of a care plan, 4) symptom management, and 5) the termination of futile treatment.

Medical fees are the fees paid to medical institutions in compensation for (and calculated based on) treatment or services provided under the national health insurance system. They are determined by the Central Social Insurance Medical Council. Patients pay a portion of the treatment fee, and the remainder is covered by public health insurance.

Kübler-Ross’s approach to diagnosis disclosure and accepting death is clearly illustrated in On Death and Dying. This book is said to have struck a heavy blow to a medical profession that regarded death as something to be concealed. Kübler-Ross went on to publish other works, but they were largely collections of essays by various authors; and in her later years, as she became interested in the occult, they included stories about the world of the dead. The work of Kübler-Ross after she came to believe in the existence of an eternal soul is not considered to relate to the hospice movement. Therefore, her first book is usually regarded as the only way to find out about her ideas during the early days of the hospice movement.

The most appropriate resource for analysing the institutionalisation of hospice care in the UK/US would have been the guidelines and manuals produced in these countries. However, the field of terminal care in Japan does not mention such guidelines, directing its attention instead to the WHO or its Regional Office for Europe. Therefore, I decided to use the WHO and the WHO Regional Office for Europe guidelines in this paper.

Tetsuo Kashiwagi authored many books. I chose two books that were written before the institutionalisation of hospice care and that I thought best outlined his ideas on hospice care, Sei to Shi wo Sasaeru – Hosupisu Kea no Jissen (Supporting Life and Death: The Practice of Hospice Care) and Shi ni Yuku Kanja to Kazoku he no Enjo – Hosupisu Kea no Jissai (End-of-life Support for Patients and their Families: The Reality of Hospice Care).

Fumio Yamazaki went on to write a lot more books, but this was after the institutionalisation of hospice care in Japan. I chose to use only this book because it best describes his ideas during his initial involvement in the hospice movement.