Journey from Life to Death:
An Anthropological Study of Cancer Patients in Japan

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Pembroke College

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Thesis submitted in partial fulfilment of the requirements
for the degree of Doctor of Philosophy
The School of Anthropology and Museum Ethnography
University of Oxford

Trinity Term 2005 [i.e 2006] (LTS 11.06)

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Abstract

The kind of diseases affecting Japanese people and the causes of death in Japan have changed a great deal in the last several decades due to various factors, most notably the advancement of medical technology and changes in life style. The number of people who die from life style diseases such as cancer, which are chronic and possibly need long-term hospitalization, increases every year.

In the 1970s the hospice philosophy was introduced to Japan from the West. It encourages patients and their families to affirm life and to regard dying as a normal process, and offers a support system to help patients live as actively as possible and sustain a sense of selfhood, autonomy, and dignity until they die. In practice, however, the dying process is still not regarded as normal in contemporary Japan and many patients fail to die in the way proposed by the hospice philosophy. There is also disagreement between the patients and the medical professionals regarding their respective idea of good death. Hospices and PCUs, which were initially developed in order to provide humane care, have become places which provide a new form of institutionalized death, and consequently constrain the patients' dying patterns.

In this thesis, I investigate the above issues from the perspectives of the anthropology and the ethnography of Japan. I demonstrate how the framework of van Gennep's rites of passage and Turner's concept of liminality can be used to analyze the current situation in Japanese hospice settings. I also perform an ethnographic analysis of Japanese attitudes towards health, illness, and death in order to illustrate the reasons why some Japanese patients fail to die a good death as proposed by the hospice philosophy.

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From the anthropological point of view, I place the dying process as the transitional period between the separation (entering the PCU) and the incorporation stages (funeral rituals) within the context of van Gennep's theory of rites of passage.

This new way of viewing the dying process provides a means to explain aspects of Japanese modern funerals which function without a notion of 'journey' and where the concept of death pollution is absent. In contemporary Japan it is the dying process that plays the role of 'journey' from life to death, and during this period many medical routines are conducted in order to try to control and remove the uncertainty, dread, and fear associated with death and dying, just as people in traditional Japan conducted funeral rituals for the same objectives.

In reality, however, it seems that contemporary Japanese people still find it difficult to accept death as it is, and that the dying are still subjects of dread. In order for them to be accepted by those around them, death and dying are reinterpreted as a meaningful experience. By explaining the dying process as a transitional period using van Gennep's framework of rites of passage, I highlight that during the dying process, death is transformed into a positive experience so that the dying can still live a socially meaningful existence. The dying process at the PCU is not only a transitional process from life to death for the dying but also a process where death is made 'good' and meaningful.

I also explain some aspects of patients' situation at a PCU using Turner's concept of liminality. Turner defines 'liminal *personae*' as structurally ambiguous and polluting, and totally under the control of the instructors of the ritual. They form a *communitas,* which consists of equal individuals submitting together to the general authority of the ritual elders. PCU patients are indeed structurally ambiguous entities who are neither alive nor dead. They are also subjects of dread, as imminent death brings uncertainty amongst the carers; they are physically weak and dependent, which makes them prone to being under the carers' control. Their pain and symptoms are also controlled by medicine. However, the hospice philosophy and the hospice setting attempt to put the patients in an unusual situation within the context of liminality. Namely, they encourage patients to be autonomous and aim to provide patient-centred care. In other words, in the hospice setting, it is the ritual subjects (the patients) who are expected to control their body and their dying process, not the ritual instructors (the PCU staff). This is the ideal; however, in this thesis I show that this ideal is not attained in reality: many patients fail to have autonomous attitudes toward dying, and experience social death before they physically die, instead of controlling their dying process. The anthropological framework of liminality provides a means to explain why this is the case.

By discussing ritualistic aspects of medical routines, I demonstrate how medical routines contribute to the smooth running of the PCU as an institution rather than contribute to patient-centred care: hospice/palliative care has become routinized because routines are beneficial for the staff and the institution. Institutionalization and medicalization of hospice care is not only a problem in Japan, but also in the West; this shows that a reason for the difficulty in practicing the hospice philosophy cannot be simply explained by cultural or religious differences between Japan and the West.

From the perspective of the ethnography of Japan, I analyze the concepts of good death and bad death in Japan. Traditionally, death which leads to the disruption of *ie* (a family household) was thought most dreadful. Death which causes a deep attachment of the soul to this world (e.g., death by accident) should also be avoided as

under this condition the soul was thought to bring misfortune to the living. As a good death, dying '*isagi-yoku*' (without regrets) was highly valued. In reality, however, it was found to be difficult to die '*isagi-yoku*', because it required great strength of spirit. More recently, the ideal Japanese death would be *rōsui* (a gradual decline leading to death in old age) or to die *pokkuri* (sudden death) so that an individual does not impose heavy burdens on the family when dying. I explore how these concepts have changed in the face of medical advances and changes in pathologies (most notably the appearance of life style diseases as major causes of death in Japan) which have changed the process of dying; for example, dying of cancer has become a challenge to both *rōsui* and *pokkuri*, as it is often neither sudden nor pain-free.

Given this situation, it is natural that the Japanese public would be attracted by the hospice philosophy, and it is interesting to see how this Western-born philosophy has been adopted by the Japanese. For example, my field observation shows that the hospice ideology of good death is interpreted by the Japanese public as dying peacefully (*yasuraka ni*) or naturally (*shizen ni*) rather than as 'living as actively as until the end' as the hospice philosophy originally proposes. It looks like the Japanese public prefers to leave its illness to take its own course rather than to seek how to 'live' until the end.

This Japanese attitude toward the dying process reflects Japanese concepts of health and illness. Although Japanese patients seem to have a passive attitude toward the dying process, they are in fact very keen to 'control' their illness and to manage their body condition using their *tairyoku* (physical power). The idea of *tairyoku* is, however, not scientific enough for the PCU staff, and the patients' belief in *tairyoku* sometimes interferes with the medical treatment. Moreover, those who seriously believe in *tairyoku* are more likely to wish to stay at the PCU even when the staff suggest to them that they go home so that they can spend fruitful time with their family before they die. Those patients try to rebuild their *tairyoku* at the PCU in order to 'cure' cancer while their pain and symptoms are well managed. This kind of patients' behaviour is contrary to the hospice philosophy, and consequently disappoints the PCU staff. More importantly, this kind of patient is not regarded as a good patient by the PCU staff, and consequently their death is not considered a 'good death'.

The hospice philosophy was introduced to Japan to meet a demand for patient-centred care and uninstitutionalized death. In reality, however, hospice and palliative care in Japan has grown more standardized and institutionalised. The ideology of good death has also been standardized in favour of PCUs as institutions, and this makes it difficult to provide patient-centred care. In contemporary Japan, death and dying are under a new form of social control, which results in institutionalized good death. There is also a gap between the hospice ideology of good death and how the lay Japanese public wishes to die. I believe that this thesis demonstrates why this has happened from the view points of both anthropology and Japanese ethnography.

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Chapter 1: Introduction

1. The structure of the thesis

Along with the modernization and development of medical technologies, the environment that surrounds the dying process in modern Japan has been changing. In funeral ceremonies, rituals on which months and years used to be spent in order to send the deceased's soul to the next world, have recently been simplified and shortened to a few days or even hours. On the other hand, the dying process has gradually become longer, and the number of people who die at hospital has also increased. Under these circumstances, the philosophy of hospice care, which offers a support system to help patients die 'a good death', has in recent decades attracted considerable attention in Japan.

The aim of this research is to examine how the changing environment that surrounds death and dying in Japan has influenced the Japanese attitudes towards death and dying in recent years. In order to do this, I investigated the experiences of dying patients receiving palliative care, because the concept of palliative care is still new to the Japanese public and this may reflect the most contemporary attitudes of Japanese towards death and dying.

Death has often been avoided as a subject of taboo and fear. Many traditional death rituals, for example, aim to send the soul of the deceased into the next world, and to purify the pollution caused by death. It took months and years for the soul of the deceased to become a harmless ancestral soul, and until then the bereaved were in

mourning and practiced various accompanying rituals. Van Gennep (1960), in his famous book *The Rites of Passage*, called this period the transitional period between the stage of separation (when death occurs) and the stage of incorporation (when the soul of the dead is considered to arrive in the next world). Turner (1969) focuses almost exclusively on van Gennep's notion of the transitional phase and calls it a liminal period. He also develops the notion of 'liminal *persona*' who is 'betwixt and between'. Hertz (1960) also focuses on the transitional period, yet his special concern is with death rituals, particularly the custom of secondary burials. For Hertz, the person first dies biologically, but his non-physical soul is regarded as being in a state of limbo, during which he is considered neither alive nor finally dead. He calls this period (between physical and social deaths) intermediary period.

In modern Japan, however, death rituals are much shorter and simplified. For many people, a funeral is regarded as nothing more than a formality. The entire funeral process is nowadays completed within a couple of days from the moment of death. In 1970s, the philosophy of hospice and palliative care was introduced from the West to Japan, which aimed to affirm life and to regard death and dying as a normal process and to enable patients to 'live as actively as possible until they die'. Under these circumstances, it can be assumed that death is more easily accepted by the public as a normal event in contemporary Japanese society, but is it really the case?

1.1. Outline of the thesis

This introductory chapter provides the necessary background for the thesis as a whole, and sets the context for the chapters which follow. I explain hospice and palliative care throughout, then also describe the field sites and my personal experience during my fieldwork. In chapter 2, in order to better understand the modern way of

death, I look at death and the process of dying from a different perspective. I discuss death rituals using van Gennep's framework of the rites of passage. I then describe some examples of funeral rites in more traditional societies, especially focusing on secondary death ritual. This provides a theoretical background on death rituals which will help understand Japanese funerals in the following chapter. In chapter 3 I discuss Japanese funeral rites both in the past and present. I explore the difference between them, and clarify the role of funeral rites in Japanese society in both times. This will help understand the role of hospice and Palliative Care Unit (PCU) in Japanese society since the dying process is always followed by death ritual, and they are associated with each other. In chapter 4 I discuss Japanese view of health and illness and the concept of good death. The findings in this chapter will be useful to understand Japanese cancer patients' attitudes not only towards their health, illness, and death, but also towards their decision making process regarding medical treatment and the process of dying.

From chapter 5 to chapter 7, the dying process in contemporary Japan is examined on the basis of my fieldwork experience at a PCU. In chapter 5, based on the framework of van Gennep's rites of passage, I define the time of entering PCU as a separation period, and explain how individuals become PCU patients. In chapter 6 I look at the dying process (the transitional period) and demonstrate what kind of death is considered good and bad at the PCU and examine factors which hinder the practice of hospice philosophy. In chapter 7, I further explore the concept of 'good death' by considering how and why a death is 'made good' at PCUs based on the framework of van Gennep's rites of passage. I also describe how a patient is discharged from a PCU. In chapter 8 I describe the hospice movement in Japan from three different points of view: medicine, the government, and the public, which helps to understand how the concept of good death has been formed in Japan society.

In the final chapter (chapter 9) I raise some issues on the state of palliative care in contemporary Japan. How do hospice and PCU serve people in Japan? What is a good death? Do the transformation and changes in trend regarding death and dying affect the way they die and their attitudes towards death? What does the dying process at PCUs represent within a context of contemporary Japanese society?

1.2. Contributions of the research

This thesis covers a broad range of topics on death and dying; i.e., death rituals, the dying process, the concept of good death, and Japanese attitudes towards health, illness, and death. It attempts to make a contribution not only to the fields of anthropology of death and dying but also to an understanding of contemporary Japanese behaviour in connection with health, illness, and death.

In anthropology, there are various studies on indigenous practices of and beliefs about death and dying (Bloch and Parry 1982; Hertz 1960; Metcalf and Huntington 1991; Malinowski 1974; van Gennep 1960). None has however taken up this theme in a modern society through hospice settings.

A unique feature of studying hospice patients is that, unlike studies of death rituals, it is possible to work with informants who will become the subject of rituals but who are still alive, and whose family members are part of this liminal process. Moreover, case studies can be supported by precise medical records, which provide access to almost 24 hour observation on each patient by medical professionals. This research is thus able to draw considerably on both patients' and their families' narratives and actions concerning their attitudes towards life, illness, death, and medical treatment. This unique feature of my research is a new approach to the study of a particular version of the intermediary period, since such information (i.e., the

narratives by the dying individuals themselves who are the subject of rituals) could not be provided in past studies of death and dying.

Up until now, most research on hospice and palliative care has been conducted from medical, nursing, and sociological perspectives, and very little has been done by anthropologists. To the best of my knowledge, there are four studies (Forss *et al* 2004; Froggatt 1997; Little *et al* 1998; Navon and Morag 2004) which try to apply the frameworks of the rites of passage and liminality to palliative care settings. Of those, two studies are conducted by anthropologists (Forss *et al* 2004; Navon and Morag 2004) and the other two are conducted by researchers who have a medical or a nursing background. Unlike my study, however, none of them either conceptualizes liminality as a demarcated tripartite process or discusses liminality in relation to ritual and performance. Froggatt (1997), in fact, argues the hospice culture in relation to rites of passage and liminality, and she attempts to demonstrate how these frameworks fit within the hospice philosophy and to theoretically explain the reason why the hospice philosophy works in reality. However, she does not discuss submissive characteristics of the passage ritual subjects (see chapter 2 for the ritual subjects' characteristics) during the liminal period, which could be patients in hospice settings. In my work, contrary to her argument, I emphasize this point and examine the conflict between this submissive nature of ritual subjects (patients) and the hospice philosophy which promotes patients' autonomous attitudes towards their dying process. By identifying the dying process as an intermediary period, I also attempt to explain the controlling nature of the medical treatment. In so doing, I illustrate the way patients' dying process has become controlled by medicine and institutions, which has consequently helped solve the above mentioned conflict for the benefit of institutions, not of patients. I also

make it clear that the hospice philosophy which promotes patients' autonomy is hard to practice in reality.

Amongst other anthropological studies on hospice and palliative care, those done by the Australian and the British anthropologists McNamara (2001; McNamara *et al* 1994; 1995) and Lawton (1998; 2000) respectively are distinctive as critical reflections upon hospice practices based on their fieldwork observation and interviews. Throughout her work, McNamara points out that there is a tension between the maintenance of the good death ideal and the maintenance of the hospice organization as part of mainstream medicine. Her studies also highlight how care for the dying and the notion of the good death have inevitably become more medicalized and institutionalized under this circumstance. Lawton also questions the hospice philosophy which encourages patients to 'live until they die'. Looking at the unavoidable effects of a patient's bodily deterioration on their sense of self, she has examined the difficulty in dying a good death within the context of the modern hospice movement. My research also examines difficulty in practicing the hospice philosophy and medicalization of hospice care; however, I approach these issues by using van Gennep's framework of rites of passages and focus on the transformative nature of transitional period (i.e., the dying process). Needless to say, during this period, patient's status changes from life to death, but I demonstrate the way that the nature of death is also transformed from bad to good. In so doing, I not only give support to the past studies but also offer a new perspective on the dying process in modern society.

In the area of Japanese studies, there are a number of studies conducted on Japanese behaviours in connection with health, illness, and death, and studies by Ohnuki-Tierney (1984) and Namihira (1987; 1990; 1993; 1995; 1996) are distinctive in regard to Japanese concepts of hygiene, pollution, health, illness, and death; however,

Ohnuki-Tierney's work was done more than two decades ago, and Naminira mainly discusses such concepts in traditional Japan. More recently, some studies deal with Japanese health related behaviours surrounding cancer, truth telling, and informed consent (Davis *et al* 2002; Elwyn *et al* 1998; 2002; Kai *et al* 1995; Hoshino 1995; Veatch 1997). However, there have been considerable changes in society from the period in which these studies were conducted. For example, the collapse of the bubble economy had repercussions on how the Japanese experience life and consequently death. One instance of these repercussions is the growing number of people who wish to know their diagnosis[1] in recent years. As a result, discussing Japanese health related behaviours from the perspective given by these authors no longer offers a vantage point when considering the most current Japanese behaviours regarding health, illness, and death. Contrary to the past studies, my thesis treats those who live in the knowledge that they are dying. In so doing, I believe that I am able to cover more recent issues and notions regarding health, illness, and death in Japan than previous studies.

The American anthropologist Long, who has done a broad range of studies on the recent issues concerning death and dying in Japan (1999; 2000b; 2001a; 2001b; 2003; Long and Chihara 2000), treats Japanese ideas about good death in her studies of patients receiving palliative care. She examines a transition of the concept of good death with the changing trend in the dying process, and claims that Japanese people no longer have a simple way to die but face difficulty in making a choice regarding how to die a good death; namely, they are at a loss in an ambiguous situation. Although she points out some inconsistencies and institutional aspects of hospice care in Japan (see Long and Chihara 2000), her analysis does not include a recent tendency in Japanese

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[1] Recently, the Mainichi (2003) reports that 90 per cent of healthy Japanese people wish to know the truth when they had curable cancer, and only 25 per cent said that they would not like to know the truth when cancer was

palliative care settings; i.e., this ambiguity is managed by controlling the dying process and institutionalizing the concept of good death. In my thesis, I expand on this point and attempt not only to find out how the concept of good death has become institutionalized within the context of palliative care in Japan, but also to understand contemporary Japanese social values and requirements that play a role for a patient in order to be accepted as a good patient; namely, a patient dying a good death. This broader treatment of a study of palliative care in Japan offers a new perspective on health related behaviours in contemporary Japan.

2. Hospice and palliative care

It is necessary first to define some consistently used terms relevant to the care of terminal cancer patients: palliative care, hospice care, and terminal care. According to a WHO Expert Committee on Cancer Pain Relief and Active Supportive Care (1990);

> **Palliative care** is the active total care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms, and of psychological, social and spiritual problems is paramount. The goal of palliative care is achievement of the best possible quality of life for patients and their families. Many aspects of palliative care are also applicable earlier in the course of the illness, in conjunction with anticancer treatment. Palliative care:
>
> - affirms life and regards dying as a normal process;
> - neither hastens nor postpones death;
> - provides relief from pain and other distressing symptoms;
> - integrates the psychological and spiritual aspects of patient care;

---

incurable. The former figure was higher and the latter one was lower than the results obtained before (The Mainichi 2003).

- offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the patient's illness and in their own bereavement.

(WHO Expert Committee on Cancer Pain Relief and Active Supportive Care 1990: 11)

In England, which is the birthplace of the modern hospice movement, palliative medicine, terminal care and hospice care are individually defined as follows:

Palliative medicine is the appropriate medical care of patients with active progressive and advanced disease for whom the prognosis is limited and the focus of care is the quality of life. Palliative medicine includes consideration of the family's needs before and after the patient's death.

Terminal care is an important part of palliative care and usually refers to the management of patients during their last few days or weeks or even months of life from a point at which it becomes clear that the patient is in a progressive state of decline.

Hospice and **Hospice Care** refer to a philosophy of care rather than a specific building or service and may encompass a programme of care and an array of skills deliverable in a wide range of settings.

(National Council for Hospice and Specialist Palliative Care Services 1995: 5)

Higginson (1996), however, notes that the term hospice is used in two ways:

The first refers to the philosophy of hospice care, which is in effect the same as the philosophy and principles of palliative care [...]. The second refers to a hospice unit. Usually this is a free standing unit with inpatient facilities, which practices palliative care emphasizing medical and psychosocial care. [...] Hospices will usually offer symptom control and terminal, palliative and respite care.

(Higginson 1996: 189)

Many hospices, though, also offer day care and home support teams, and some do not offer inpatient care (Higginson 1996: 189). Therefore, the term hospice or hospice care refers to a philosophy of care which centres around palliative care, and the palliative care given to patients during their last few days or weeks or even months of life can also be called terminal care.

In Japan, hospice care, terminal care, palliative care and palliative medicine[2] all refer to the same thing (Kawano and Hirayama 2000: 272). This may be related to the Japanese holistic approach which does not differentiate one meaning from the others. In the West, where the tendency toward fragmentation and specification is more dominant, despite the overlap in reality, these three different terms specify slight differences. On the contrary, it can be said that Japanese people wish to retain a holistic view of care, and this may have resulted in the ambiguity between the terms, hospice care, palliative care and terminal care. According to Kawano and Hirayama (2000: 272), however, in Japan it has recently become more common to use the term palliative care or palliative medicine, rather than hospice care and terminal care. In fact, more than half of the institutes or units established under the concept of hospice care are called palliative care units (PCUs) rather than hospices.

In October 1991, the Japanese Association of Hospice and Palliative Care was established[3]. The association refers to the concept of hospice and palliative care as:

> [the] care which is offered by a team consisting of various professionals to improve the quality of life for patients and their family members, and to enable them to live their lives as comfortably as possible as human beings with dignity. Five important concepts are:

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[2] The Japanese words for these concepts are, *hosupisu kea, tāminaru kea, kanwa kea, and kanwa iryō* respectively.
[3] More details on the Japanese Association of Hospice and Palliative Care Unit will be given in Chapter 8.

1) The hospice program affirms individual life and respects 'the dying process', which inevitably occurs to every person;
2) Hospice care neither hastens nor postpones death;
3) Hospice care relieves pain and other burdensome physical symptoms;
4) Hospice programs assess and respond to psychological and socioeconomic needs and support patients seeking the meaning of his or her life (spiritual care);
5) Hospice programs provide support to family members in their struggle while their loved one is alive and after his or her death.

(The Japanese Association of Hospice and Palliative Care 1997, cited in Long and Chihara 2000: 166)

The concept of hospice/palliative care in Japan, proposed by the Japanese Association of Hospice and Palliative Care Units is very similar to the definition of palliative care given by the WHO above. In Japan, all three terms (i.e., hospice, palliative and terminal care) are not officially defined individually, and they are conceptually equal, as mentioned above. To avoid confusion, in this paper the term palliative care is used in preference to hospice care or terminal care, as palliative care is the core care practiced in both cases. The term hospice will be still used, when it refers to a proper noun, i.e., St Christopher's Hospice, and when it refers to a philosophy of care.

3. The hospice movement in the West

The use of the word 'hospice' to refer to a philosophy of care or a hospice unit is a recent phenomenon. The word 'hospice' comes from the Latin '*hospitium*', which means a shelter for pilgrims and travellers. This existed in Rome from the seventh or the eighth century (Maruyama 1999: 6). 'Hospitium' in turn originates from the Latin 'hospes' which means both 'guest' and the 'host' who welcomed an unexpected visitor

(Maruyama 1999: 5; Kawano and Hirayama 2000: 266). 'The actual idea of caring specifically for the dying seems to have begun in the Dublin Hospice in the nineteenth century, where the old tradition of hospice care (i.e., care for the sick and dying with respect and compassion) was transformed into a new understanding of the needs of the dying' (Maruyama 1999: 10). This new understanding developed into the hospice philosophy and led to the hospice movement in the U.K. which is represented by the establishment of St Christopher's Hospice in London in 1967. The hospice philosophy then spread all over the world including Japan.

Higginson (1996: 184) argues that 'changes in the nature of diseases during the last several decades have led to many more people dying from chronic diseases or incurable diseases in later life rather than suddenly from acute diseases, such as infection'. Under this circumstance, more people are likely to experience a period living with incurable disease within the process of dying. In order for the patients to be able to live with their diseases in dignity, it is very important to remove as much pain and uncomfortable symptoms as possible. In fact, 'uncontrolled symptoms or severe patient and family distress while a patient has a progressive illness severely inhibits the patient's quality of life and is believed to impact on the carers' or family members' subsequent resolution of their grief' (Higginson 1996: 184). Hospice philosophy was established in order to improve this condition.

The history of the hospice movement can not be described without acknowledging the effort of Cicely Saunders. She was the first person to begin offering more care-centred treatment[4] to dying patients. Saunders engaged with research on pain control, and took an important role in improving the methods (Maruyama 1999: 10).

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[4] This means treatment which focuses more on improving quality of life of patients rather than treating disease as curative.

She also opened St Christopher's Hospice in London for in-patient care in 1967 and for home care in 1969. The hospice also provided bereavement services, and enjoyed some financial support from the National Health Service (Munley, 1983: 29, cited in Maruyama 1999: 10; Saunders 1993: 3).

The hospice movement provided a radical critique of patients' dying processes within hospitals, which it considered to be too impersonal, medicalized, and technological (James 1994: 103; Abel 1986: 71; Moller 1996:39, cited in Lawton 2000: 12). In the period in which the hospice movement arose, death had started to be regarded as an inevitable companion of life and therefore the appropriate care for the dying became a concern for hospice pioneers. Consequently, hospice philosophy gave emphasis to care rather than cure, and to the improvement of the quality of life rather than its quantity (i.e., extending life expectancy as a result of aggressive life-sustaining strategies) (Munley 1983: 35; DuBois 1980: 73-4, cited in Lawton 2000: 12; Higginson 1996: 184). Additionally, hospice philosophy aimed at patients being able to live with human dignity until their last day. Indeed, throughout the dying process, many patients encounter several problems that diminish their dignity, such as incontinence (see Lawton (2000) for an example). Dignity, in this sense, includes an aesthetic presentation which is also a part of the presentation of self. Not only those who are dying but also the carers who watch the dying are affected by the appearance of patients. What the dying need under this circumstance goes beyond the practical elements, such as being helped to eat, but also the preservation of human dignity. In order to realize this goal the quality of care traditionally offered at institutions needed to be improved. For example, the number of nurses or carers had to be increased in order to provide patients with more meticulous attention and care in practice. Hospice

philosophy resulted in differentiating institutions (i.e., hospitals and hospices/PCUs) within the context of the quality of care.

At almost the same time as the hospice movement developed in Britain, the American psychiatrist Elizabeth Kübler-Ross published a book called *On Death and Dying*. She interviewed a number of dying patients, and described the five stages people usually experience when coming to term with a terminal illness: denial, anger, depression, bargaining, and acceptance (Kübler-Ross 1970). Her studies broke new ground in understanding the process of dying, and this model gained rapid and widespread acceptance amongst health care professionals and the general public, and has since been used and taught all over the world (Buckman 1992: 33)[5].

Hospices have expanded rapidly and the form of hospice care has also become diverse since its birth in the late 1960s. In 2005, in the UK and the Republic of Ireland, there are 220 in-patient units, 263 day hospice services, 462 home care or hospice-at-home teams, 293 hospital support teams, and 68 hospital support nurses[6] (Hospice Information 2005).

4. The hospice philosophy

The hospice philosophy encourages patients and their families to affirm life and to regard dying as a normal process. At the same time, the philosophy offers a support system to help patients live as actively as possible and to sustain a sense of selfhood and

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[5] Buckman argued that although Kübler-Ross's work was unequivocally important and new, there have been many difficulties in applying this framework to the practical care of patients facing death. In particular, the system does not often 'fit the bill' in terms of what happens in clinical practice, and frequently does not assist the professional in predicting what is likely to happen next, or by what criteria he or she can assess the patient's reactions (i.e., dying people may not follow all five stages, or may experience them in a different order or some may be simultaneous. Some may not accept their death until near the point of death, but others may accept it sooner.) (1992: 33). Although a number of the model's deficiencies have been pointed out, the model has been widely accepted as a basic idea to understand the process of dying.

dignity until they die. It also stresses the importance of respecting patients' autonomous attitudes especially towards decision-making. Open discussion between patients and medical professionals is therefore strongly encouraged. The ethos of hospice care is that the terminally ill should be able to approach death as themselves, to live in their own way until the final hour. In Japan, a defining feature of hospices is described that they resolve to aid patients in '*Saigo made sono hitorashiku*' which is to say, 'As myself, until the end'; this ideology aims to help patients live as actively/comfortably as possible until the end and to ensure a 'good death' for patients[7].

4.1. The concept of 'total pain' and team care

The hospice philosophy stresses the concept of 'total pain' and the team care approach in order to achieve its alleviation.

Hospice proponents criticized hospital practitioners for focusing exclusively upon the treatment and control of a patient's 'disease', rather than treating the patient as a 'whole person' (Lawton 2000: 13). Needless to say, pain relief is very important for patients, and it should be a primary concern. Saunders *et al* (1983 [1995]) points out that physical pain is inextricably entwined with other pains, such as psychological pain, social pain, and spiritual pain and calls this 'total pain'. Twycross (1999) further explains each pain as follows:

(1) Physical pain - Other symptoms; adverse effects of treatment; insomnia and chronic fatigue

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[6] Hospital support teams and hospital support nurses provide patients with specialist support services in general hospitals (Clark 1993:167).

[7] 'Live '*saigo made sono hitorashiku*'' is a phase often used in introductory leaflets which are published by PCUs or hospices for patients and families.

(2) Psychological pain - Anger at delays in diagnosis; anger at therapeutic failure; disfigurement; fears of pain and/or death; feelings of helplessness

(3) Social pain - Worry about family and finances; loss of job prestige and income; loss of social position; loss of role in family; feelings of abandonment and isolation

(4) Spiritual pain - Why has this happened to me?; Why does God allow me to suffer like this?; What's the point of it all?; Is there any meaning or purpose in life?; Can I be forgiven for past wrongdoing?

(Twycross 1999: 66)

Saunders (1993) remarks that the division of a whole experience of 'total pain' into these four categories helps many workers to be aware of the components of such a situation. This helps to promote a team care which the hospice philosophy stresses. The team is usually comprised of multi-disciplinary staff, including not only doctors and nurses, but also other professionals such as social workers, chaplains, counsellors, physiotherapists, occupational therapists and voluntary workers.

It is pointed out that a perspective of 'total pain' confounds the conventional medical models, as well as broader Cartesian notions of a mind-body dualism (Saunders 1993; O'Brian 1993, cited in Lawton 2000: 13). However, the concept of total pain might be a product of conventional medical models, which have fragmentary tendencies of distinguishing mind and body, physical and mental, rational and emotional, as independently constituted entities. Therefore, the concept of total pain, which firstly splits pain into types and then puts them all together as a whole, seems to derive from the Western epistemological dichotomising way of thinking.

4.2. Hospice as family and care for families

The hospice philosophy not only promotes care for patients, but also for their family members. According to Dubois (1980: 12), 'hospice advocates sought to provide patients with a more personal form of care by stressing the importance of including the family as well as the dying person in the main unit of care' (cited in Lawton 2000: 12). Munley (1983: 95) suggests that this is combined with the idea that hospice staff should provide an environment similar to an extended family (cited in Lawton 2000: 12). Furthermore, Saunders (1965) aimed for St Christopher's Hospice to become 'the kind of family and home that can give the kind of welcome and hospitality of a good home' (cited in Lawton 2000: 12). The idea of team care plays an important role in making this possible. The hospice/palliative care team is there to share the distress and suffering endured by patients and their family during the process of dying.

Furthermore, it should not be forgotten that the hospice philosophy includes not only a support system to help the dying, but also to help the family cope during the patient's illness and in their own bereavement. In this respect, it seeks to provide a more traditional type of care for the dying, which places the emphasis on family and community networks.

4.3. Hospice and 'my own death'

Lawton (2000) argues that the emergence of the modern hospice movement can be understood as a direct and explicit response to the development of the modern conception of self:

> Hospice pioneers advocated a model of care in which patients were informed frankly and openly of their decisions surrounding their treatment and care (Abel 1986: 73). [...] Indeed, one of the central goals of the modern hospice movement, as Kearl highlights, is to enable patients to retain control of their lives until death (1989: 483), since their 'basic human rights are seen to be violated when they lack the knowledge and power to make decisions' (1989: 483).
>
> (Lawton 2000: 13)

Ariès (1974)'s argument supports this statement. He remarks that, from the fifth to the twelfth century in Europe, death and dying was a more familiar event in people's everyday life. The dying person could organize their own death ritual and know how it would proceed, since they would have attended others' rituals in the past. The ritual was conducted and accepted naturally. Death was not the act of an individual but of the community, since it involved many people during the dying process and at funerals. Ariès calls death at the time, 'tamed death'. In the twelfth century, however, the emergence of individualism became prevalent, and with it the emergence of a supposedly 'hidden death' (Ariès 1981: 570, cited in Lawton 2000: 9). This is 'a phenomenon which occurs within a medical setting and which began very discreetly in the 1930s and 40s and became widespread after 1950' (ibid.). Home became 'inappropriate as a space for dying' (Hockey 1990: 36, cited in Lawton 2000: 9), and more deaths started to occur not at home surrounded by familiar people, but at a place which was more segregated from ordinary people, such as a hospital. Certainly in the UK there was a sharp increase in deaths occurring in hospitals and other places caring for the sick (e.g. nursing homes) from the mid-1960s to 1989 (Lawton 2000: 9).

Modernization further encouraged 'hidden death'. Development in medical, surgical and pharmacological technology resulted in the institutionalization of death and dying, which encouraged the removal of mortality from the home to the hospital.

Death came to be treated as a process of medical control rather than as a natural occurrence, resulting in the isolation of the dying from their family members. Additionally, the transition to a nuclear family structure due to the increased social and geographical mobility of its members, as well as the increased involvement of women in the labour market, have had the effect of causing 'a progressive reduction in the availability of unpaid lay carers able to look after a dying patient at home' (Field and James 1993: 7).

Advancing medical technology brought about the myth that all disease could be cured. This also resulted in a new way of dying, —what Illich (1976: 180-181) describes as 'death under intensive hospital care', which is not only hidden but also painful and humiliating. Under these circumstances, as Ariès (1974) notes, the initiative in the dying process has passed from the dying person to the doctor and the hospital team.

Institutionalized death in a modern hospital may have made many contemporary people recall the traditional concept of death, where the dying were able to take some initiative. Institutionalized death may have also encouraged people to think 'I want to die in the way I wish' or 'I want to have my own death'. This ownership of death leads to an idea of control over death, as opposed to being controlled by medical professionals. This point of view also enables the dying to spend the rest of their life in the way they prefer most. For example, they could accomplish uncompleted tasks before death, which might help them die without regrets and achieve closure. This is hard to be realized if patients are not fully aware of the true diagnosis. When the medical professionals had the initiative in the dying process, patients did not have to know their true diagnosis, and it was often not talked about between medical

professionals and patients. However, the shift from implicit understanding to explicit discussion was necessary for patients to own their own death.

In this way, the emergence of the modern hospice movement can also be explained as a response to the pursuit of 'my own death'.

Having 'my own death' has been accomplished by more effective forms of pain control which the hospice movement pioneered. This brought an additional way of helping the dying patient to retain a sense of control so that they could die in the way they wished. 'Freedom from pain while in a conscious and alert state, allows dying patients to retain control over as much of their lives as possible and to complete their unfinished business prior to death' (Skinner Cook and Oltfenburns 1989: 6, cited in Lawton 2000: 13). This circumstance allows patients not only to control their lives and to make decisions concerning the treatment and care given, but also to face the fact that they are in the process of dying regardless of their will. Some may accept the fact, and may try to complete their unfinished business, as Skinner Cook and Oltfenburns mention above, but others may think that there is no meaning for them to live any more, as they are a burden to their family and friends. Yamazaki, who is a director of St John's Sakuramachi Hospice in Japan, says that:

> Removing pain means that patients go back to being a person. Going back to being a person means that he or she has to be amidst a great deal of psychological suffering.
>
> (Yamazaki 2000: 143)

Lawton (2000: 13) also notes that:

> If 'retaining control' was one aspect of personhood striven for in a patient's approach to death, it was also assumed that the patient would want to engage in meaningful relationships with others.
>
> (Lawton 2000: 13)

It may be hard for patients to retain control when they have an incurable disease, as their control is limited by the physical disability they suffer from, or from which they will eventually suffer. It can be said that this may generate more suffering, especially if patients want to have meaningful relationships with others. They may be worried that they become a heavy burden to their family and friends. Though the pain is successfully removed this does not mean that patients will recover from a disease. They are still in the process of dying. When they cannot find reason to live, they may experience a great deal of suffering, and seek meaningful relationships with others to resolve their existential sufferings.

5. Description of the field sites

The palliative care unit (PCU) where I conducted fieldwork was established in September 1988 with twenty-eight beds within Higashi Sapporo Hospital[8]. There are two full-time doctors, twenty registered nurses, five nurse's-aids, one medical social worker, one dietician, one pharmacist, one music therapist, and many voluntary workers functioning as a team.

Most PCU patients suffered from cancer, and were at the terminal stage. The patients' average length of stay at the PCU was approximately 45 days. In many cases, entering the PCU was the patients' own choice, or they decided to do so because it was recommended by their family or acquaintances who had heard of the PCU, or by their previous doctors. In case of the PCU at Higashi Sapporo Hospital, a number of patients were observed to be from outside Sapporo. This can be explained by the fact that there

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[8] Higashi Sapporo Hospital has 250 beds in total. There are many other departments, such as oral surgery, internal medicine, digestive organ medicine, respiratory organ medicine, surgery and anaesthesia. The palliative care unit has out-patients' clinic as well. PCUs are called *pī-shī-yū* or *kanwa kea byōtō* in Japanese.

are only three PCUs throughout Hokkaido Prefecture (as of September 1st, 2001), and all of them are located in Sapporo (The Japanese Association of Hospice and Palliative Care Units: 2001), forcing many cancer patients who wish to enter a PCU to leave their home towns.

According to the hospital staff, approximately 60 percent of patients know their true diagnosis[9]. Although it is called a Palliative Care Unit and some patients knew this kind of institution was also called a hospice, some inpatients did not know that the place was designed for terminal cancer patients. Many of them understood that the PCU was a place to preserve or even regain their health[10]. It is usual that family members of elderly patients ask medical professionals not to tell them the truth, as they sometimes suffer from dementia, or the family find it harsh to tell the truth to them. However, I got the impression that many of those who suffered from severe and progressive physical deterioration knew that they were not getting better. Some patients preferred not to be told, but later they typically started to ask medical staff subtle questions, such as "Is my tumour malignant?" or "It is not curable, is it?" Medical staff usually chose words carefully, but hardly told them a lie. They typically answer those questions as follows: "Do you think it is malignant?", "Do you want to talk to your doctor about it?", and "What made you think so?" instead of denying it straight away.

In general, however, the precise prognosis is impossible to give. This is why many doctors do not tell patients their prognosis unless they are specifically asked. Otherwise, it is given to patients only when patients believe that they will live much longer than a doctor's prediction. Then the prognosis is given in order to modify the

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[9] This means that approximately 40 percent of patients; 1) do not know the diagnosis at all; 2) know the diagnosis but do not know about further metastasis; and 3) know the diagnosis but they do not know that they are in a terminal stage.

[10] This is probably because in Japanese *kanwa kea byōtō* simply means a ward to relieve pain. Additionally, *pī-shī-yū* (PCU) is just a sound from the English alphabet, which does not mean anything in Japanese.

patient's attitudes towards the rest of his or her life. Yet the approach is still somewhat nuanced. Doctors would typically say, "Please do not think you can see cherry blossoms again" or "You may not be able to wait until the snow melts away", instead of giving a 'verdict'. There are many cases where doctors miss an obvious chance to tell their patients about the progress of their disease. This is firstly because it is not a good news, and secondly because the condition is incurable. If it is curable, the patient must immediately be informed so further treatment can be arranged. In the case of terminal patients, doctors have to use their discretion as to the appropriate time to discuss their condition.

There is nearly a complete absence of regulations in the PCU, and to complement the care provided both by the medical and non-medical staff outlined above patients are encouraged to interact with their families as much as they can throughout their stay at the unit.

The PCU is well equipped to facilitate this. There is a kitchen for patients and family members where they can cook their own meals, a family room where they can stay overnight, and a day room where patients, families, and PCU staff can spend some time together. The unit also has a conference room where medical professionals, patients and their families can hold meetings to discuss the disease and future treatments. There are three different types of patients' rooms: 14 single rooms, three double rooms, and two rooms that house four patients. Each room has different facilities depending on its size. The best-equipped room has its own toilet and shower, an air conditioner, a TV set, a refrigerator and a telephone. Meals are provided three times a day to each patient's room. The menu is not fixed; it is unique to each patient under the advice of a dietician and depending on patients' preference. A dietician visits patients on request at any time to discuss their eating preferences and to assess any

physical conditions affecting their eating ability (i.e., dysphagia). Nightwear is provided by the hospital; however, all patients are encouraged to wear their own.

There are many weekly or seasonal events held at the PCU with the assistance of voluntary workers; for example, tea and coffee time, musical concerts, film nights, art exhibitions, a summer festival, a karaoke party, and a Christmas party.

From July to September 2000 I briefly visited one Christian, one Buddhist, and one public hospice with a Christian chaplain. These were respectively called Yodogawa Christian Hospital in Osaka, Nagaoka Nishi Hospital in Niigata and Rokko Hospital in Kobe. Yodogawa Christian Hospital is famous as it is the first palliative care service established in Japan. They have a hospice ward[11] with twenty-three beds, and two Christian chaplains from the hospital evangelist department. Nagaoka Nishi Hospital has a Buddhist palliative care ward, called Bihāra, with twenty-two beds. Bihāra is the word advocated in 1985 by Dr Takashi Tamiya, a hospice director. He explains that the name is derived from the Sanskrit word '*vihara*', referring to a Buddhist temple or monastery, or to a place in which to clear one's mind through rest or contemplation (Nagaoka Nishi Hospital Web Site: 2005). There is a Buddhist monk who works full-time at Bihāra. A hospice ward (with twenty-three beds) at Rokko Hospital is unique in having a Christian chaplain despite the fact that it is a public hospital[12]. I also had an interview with the chief nurse at a private surgery, Tanaka Surgery in Miyazaki Prefecture. Another nurse took me to the houses of some patients receiving home care.

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[11] They call it *hosupisu byōtō* (a hospice ward) in Japanese.
[12] Public hospitals in Japan are usually non-religious institutions.

6. Fieldwork methodology

The ethnographic methods used during my fieldwork were direct interviews and long-term participant observation at the palliative care unit in Higashi Sapporo Hospital from November 1999 to October 2000. The main reason I chose Higashi Sapporo Hospital was that I knew a doctor working there. She played the role of intermediary between the hospital director at that time, Dr Kunihiko Ishitani, and myself. I had nonetheless to undergo a formal procedure in order to be accepted by the hospital as a researcher. Higashi Sapporo Hospital had been accepting many researchers who enjoyed a very open atmosphere. However, the hospital staff told me that they had never accepted anybody who would conduct fieldwork for as long as mine and therefore considerable time was spent deliberating how and where to locate me in the hospital setting. In the end I was allocated a desk at the doctors' station on the top floor of the hospital building where I could conduct my own work, and I was entitled to use many of the facilities and materials (i.e., computers, a photocopier, the hospital journal library and so on) that other doctors used. Due to the nature of my research, which is qualitative rather than the quantitative one with which medical staff are more familiar, my research drew considerable attention from other hospital staff[13].

How I should label and present myself to patients within the PCU was also carefully considered before entering the field site. Obviously patients should be fully informed about my research, but there was agreement between the hospital and myself that my presence within the PCU environment had the potential to be too awkward and distracting to patients and staff alike if I acted solely in a research capacity. It was agreed that I should have a role that would give me a legitimate reason to spend large

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[13] I gave two one-hour seminars to medical staff at the hospital during my stay there.

amounts of time within the PCU. After some discussion with the hospital staff, it was decided that I should work in a volunteer capacity as this would allow me considerable contact not only with patients but also with the PCU staff and other volunteers. In this manner, I started to conduct my fieldwork, wearing an apron and helping at almost all the events held by volunteers. For example, serving patients tea and refreshments at tea-time familiarized me with the atmosphere of the PCU, and also made it easier for me to meet each patient, since I had to visit all patients' rooms to ask whether or not they wanted to have a cup of tea. This also helped me obtain access to all PCU patients including some I would have had no opportunity to know otherwise. For instance, patients who were not happy to see people from outside or patients with whom I had little in common[14]. I could also talk to patients' families in a very informal manner. Many family members were actually very pleased to see somebody like me from outside, as they usually spent most of their time confined in the patient's room, and they seldom went out except when they had to go shopping for the patient.

The chief volunteer always introduced me to patients as a researcher, although I was in an apron, and I was somewhat concerned that patients might find it too confusing if I wore two hats simultaneously. However, the outfit of a voluntary worker may have had a stronger image than I had expected, and it seemed that I was categorized as one of the student volunteers from some university, rather than a researcher wearing an apron. I actually did not encounter any obvious problems with how I should present myself. It seemed to be the most viable option at the time. Yet, I gradually realized that the outfit of a volunteer limited the range of information I could

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[14] It was easier for me to find common interests with younger female patients than older males. I could start a conversation more easily with them: I usually praised their nice pyjamas or talked about recent TV programmes. Most of them were also quite talkative. On the contrary, older male patients were usually quieter than female counterparts. I often did not know what to say after some small talk. When patients were very quiet, I usually

obtain. I had a great many conversations with patients and their family members, and it was an ideal way to get to know patients and the PCU itself. However, I started to wish for more than the usual daily conversations; that is, access to the conversations between patients/families and medical professionals, and interactions between them during meetings concerning a patient's diagnosis, prognosis or future treatment[15].

In January 2000, after two months, I decided to change my appearance from that of a volunteer in an apron to a researcher in a white coat, identified with medical staff. This brought about a great change in my research. The white coat enabled me to attend doctors' visits to patients[16], rather formal meetings between a doctor and a patient or a patient's family where the true diagnosis and prognosis were given, and orientations for new PCU patients and their families. I could also sit in a consultation room for PCU outpatients. I was usually introduced to patients and their families as a student who was conducting research on palliative care in another institution, and was visiting Higashi Sapporo Hospital for training[17].

Possibly due to the white coat I was wearing, I was entirely trusted by patients and their families, and was never refused a seat behind a doctor, where I wrote down the conversations that occurred. This would not have been achieved if I had been working

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asked them if I could massage their body. This enabled me to be with patients for a long time even without talking much and I could still establish some rapport with them. Yet I found it difficult to offer male patients massage.

[15] There was a female patient (Ms Shintani, whose name will appear in a later chapter) whose room I used to visit everyday. One day I heard from her doctor that she would have a meeting with him concerning the condition of her disease. I asked her whether I could attend with her, but my request was refused. She told me that, "It is a very private matter." I speculated that she might have thought that I was solely a volunteer, who should not be party to matters concerning medical professionals.

[16] There are three types of doctors' round. Each PCU doctor informally visits patients in their charge daily. On Fridays, two PCU doctors visit all the patients in the ward together with other staff such as a medical social worker in order to grasp the current situation of each patient, and to discuss strategies for pain relief. On Tuesday, staff from outside the PCU, such as hospital director, director of nursing, and deputy directors of nursing, go round all PCU patients. (This was called *inchō kaishin,* hospital director's round.) The total number of this group was approximately ten.

[17] On one occasion when a doctor introduced me to a patient, the doctor explained my research in so much detail to the patient that she seemed scared by it and she refused to talk to me after that. Since then, we had agreed that I would be still introduced as a research student to patients, but it would not be necessary to explain my research content to them unless they asked.

in an apron, which would have been out of place in such a situation. I thus collected tremendous amounts of important information between January 2000 and my departure in September, and most of the data I employ in this thesis was obtained during that period.

In this manner, throughout the year, I spent most of my time in close contact with patients, families, and medical professionals in order to conduct direct interviews and long-term observation. I attended daily conferences for PCU staff, doctors' meetings with patients and families, and PCU outpatients' consultations, concentrating on recording the speech and actions of patients, families and medical professionals which I could later analyze in line with my research. I was also allowed to look into patients' medical records at the nurse's station. I should note that many patients' names will be mentioned throughout this thesis but they are all fictitious.

I had two important informants, female cancer patients, Ms Yasukawa (aged 36) and Ms Shintani (aged 42). I started to see them when they entered the PCU, and used to visit their room daily. I attended Ms Yasukawa on her deathbed in March 2000. As regards Ms Shintani, she lived for six more months after I left Sapporo for Oxford. I also visited some other patients[18] regularly but much less often for the reason I will give in the next section. While I was seeing these patients continuously, I was also observing other patients at particular occasions, such as PCU admission, taking a medical examination, being given a result of an examination, and making a decision concerning pain and symptom control. Many of these patients were observed only once[19].

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[18] The number of patients differed from time to time, depending on how busy I was with my two main informants; however, the approximate number was usually five patients.

[19] I could observe those patients mainly because PCU staff kindly asked me whether I was interested in seeing them when any relevant events came up. For example, some doctors typically asked me, "Miss Okamoto, would you like to come with me now? I am having a meeting with a patient and his family to discuss future treatments."

6.1. Difficulties of fieldwork

Working on such a sensitive topic presented a number of personal and methodological difficulties. For one, it is ethically problematic to give an explicit interview or questionnaire to dying patients about death. Instead of focusing on formalised individual opinions and responses, therefore, my research employed the usual anthropological research method of participant observation, which enabled me to analyze the dying's attitudes towards death and dying by examining their actions and behaviours within the context of everyday existence. This methodology seemed to resolve the procedural problem one encounters at a PCU.

One of the aims of my fieldwork was to obtain information from conversations with patients; therefore, I made the greatest effort at the PCU to talk to them. Nonetheless, it was really difficult for me to find even the right greeting for patients who were obviously suffering. I was once asked by the chief of the volunteers to visit a female patient, in her mid-forties, with intestinal cancer, as she was depressed and sobbing every day. When I visited her she was, as I expected, very depressed, but I asked her how she was in a rather cheerful tone of voice, as I did not know what to say to her. As soon as she heard me she looked at me and said, "Why are you so healthy and energetic? I feel so angry when I see somebody like you. It's not fair!" This response was much unexpected and horrified me a great deal. I apologized to her, and walked out of the room, very upset. For a while, it became very difficult for me to see patients after this incident.

Since then, I became more careful when talking to patients, and did not encounter any obvious problems. Despite this, it was still difficult for me to talk to the dying. Those who had just entered the PCU were usually easier to talk to as their

physical condition was usually slightly better than those who had been there longer. However, the fact that the average length of stay at the PCU is approximately 45 days, made it impossible for me to establish good relationships with as many patients as I had expected. In reality, many patients at the PCU fell into a coma, or even if this did not happen they often became difficult to talk to due to their physical deterioration many days prior to death. Therefore, in fact, the period that allowed me to establish a good relationship with patients was very limited. Furthermore, especially if a patient was an elderly male, I found it difficult to come up with an appropriate, common topic at conversation[20]. Probably for this reason, I unconsciously chose relatively young female patients (Ms Shintani aged 42 and Ms Yasukawa aged 36) as my main informants at the PCU.

I was first encouraged to visit these by the chief of volunteers and by medical staff, as both patients were female, and their age was close to mine. They were still young and needed somebody with whom to talk. In fact, upon my first visit, both of them easily accepted me and even asked me to visit them every day, which encouraged me to go and stay with them again. I sometimes brought them some special seasonal sweets or souvenirs from somewhere outside Sapporo. It was also my routine to take Ms Shintani in her wheelchair to a conservatory on the top floor of the hospital building. I became very close to them due to our daily meetings. In due course, I became the main carer for both patients, and even medical staff sometimes asked me for advice concerning these patients. It may also have been beneficial for these paid workers to keep me as a carer, because this led to a reduction in the amount of their work without any additional expense. This may explain why I was admitted to visit the

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[20] I found elderly males much quieter than female counterparts. They also tend not to talk much about themselves and their family. I usually gathered more personal information on elderly male patients when their carers (usually

patients freely and to spend a large amount of time with them although I possessed no medical qualification.

I actually hoped to have more patients to observe than the two mentioned above. However, visiting two patients daily was physically very demanding, and I had to give up the idea of expanding the sample, although I made many attempt to increase it. The reason why I felt it demanding was mainly because of the different notion of time entertained by dying people.The notion of time we employ in our everyday life should not be used when talking to PCU patients: their lives are too fragile and vulnerable to think about even the near future; their bodily condition changes constantly, and acute pain frequently prevents them from continuing what they were doing only a minute before. For these reasons, it became clear to me that my policy of often leaving things until tomorrow should not be employed with PCU patients, and this made it difficult for me to visit them simply when it suited me. The following examples illustrate how I came to acknowledge that PCU patients' notion of time differed from that of healthy ordinary people.

6.1.1. "I want to show you something..."

There was a young female patient with lung cancer in a room with four beds. She once told me that she wanted to show me something on the following day, when I next visited her. Yet, I could not visit her on the following day due to some miscellaneous duties, and the next time I was able to go to her room was a few days later. When I went to see her in her room, her bed was empty. Then one of the patients in the room told me that she had been moved to a private room, as her condition had

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women) were present so that I could find something to talk about when I was alone with those male patients.

suddenly worsened. As soon as I heard this, I left the room for the private room, but there was a card in front of the door, saying 'No Visitors'. After all, I missed her. She had passed away without seeing me again. Her 'tomorrow' meant nothing else than 'tomorrow'. I regretted that I had not understood the condition in which cancer patients were placed, and lamented over my selfishness.

6.1.2. "I might die tomorrow..."

An old male patient in a room for four was very friendly and talkative. He once told me that he wanted to have some wine, and asked me to go and get it for him. It was already quite dark outside and snowing heavily. The closest supermarket was quite far away. The woman who was his main carer said to him, "Don't be so difficult. It's quite late, so ask her tomorrow if you still want it." He replied, "I need to have some now. I might die tomorrow, you know." Then I offered to buy some for him. It was not actually a pleasant day to go out at all, but I wanted him to enjoy some wine if he could. As had been expected, he was overjoyed with the wine. He offered me a glass, and we spent a great time drinking together.

A few weeks later, he passed away. Then I happened to see his carer at the PCU, and she told me how much he had enjoyed the wine that I bought for him.

As these examples show, the notion of time that cancer patients have is confined and limited. Tomorrow, or even a minute later, is not guaranteed, and they live 'moment by moment'. When meeting PCU patients, it is important to remember that one's own circumstances should not take precedence over theirs. This means that one should move around the patient, who is the central figure, and this explains why I could not cope with visiting any more than two informants regularly during my stay in the PCU. I attempted to take on more, but I soon realised that seeing two patients was actually an upper limit.

7. Summary

In this chapter, I have discussed the origin and philosophy of hospice and palliative care. I have also illustrated the field sites, the research methodology, and experiences I went through in the course of my field work.

The modern hospice movement occurred as a result of pursuing an anti-institutional approach to death. The modern way of dying in institutions such as hospitals removed the initiative of the dying process from patients to medical professionals, and made it difficult for patients to own their own death. The hospice philosophy attempted to learn from traditional methods of caring for the sick and dying (i.e., with respect and compassion) and reincorporate this into a modern setting.

Chapter 2: The Process of Dying

In this chapter, death and the process of dying in more traditional societies, where modern medicine does not prevail, will be examined, and the way death is treated will be investigated with regard to change, process and passage. Death rituals as signifying an intermediary period and the concept of bad and good death will also be explored, which will also help us to further understand the dying process in modern society.

1. Death rituals in anthropology

The study of death is a persistent feature of social and cultural anthropology, a special cross-cultural interest in death rites having developed since the late nineteenth century. Van Gennep's work on rites of passage (1960) laid the groundwork for the recognition of many of the phasal elements that characterise attitudes and practices with regard to death, with funerals constituting one of a large class of rituals sharing the common tripartite structure of separation, transition and incorporation. A person is detached from one status (as a living being with social rights and duties) and reincorporated in another (as a dead ancestor, sometimes also with rights), after passing through a transitional period. Van Gennep called this *the pattern of the rites of passage*, and illustrated the way in which this recurred at key occasions throughout the life-cycle, such as birth, death, initiation and marriage. He also pointed to the

existence of transitional periods which sometimes acquire a certain autonomy. According to Van Gennep's survey of death rituals, for instance, rites associated with death are mainly undertaken during a transitional period in order to incorporate the dead into another world, and funeral symbolism seems to be dominated by the concept of transition. He states that:

> On first considering funeral ceremonies, one expects rites of separation to be their most prominent component, in contrast to rites of transition and rites of incorporation, which should be only slightly elaborated. A study of the data, however, reveals that the rites of separation are few in number and very simple, while the transition rites have a duration and complexity sometimes so great that they must be granted a sort of autonomy. Furthermore, those funeral rites which incorporate the deceased into the world of the dead are most extensively elaborated and assigned the greatest importance.
>
> (van Gennep 1960: 146)

Van Gennep points out that many societies regard the world of the dead as an island, a citadel surrounded by walls, or as situated on a high mountain, or in the interior of a mountain. 'What is important to us in these cases is that, since the deceased must make a voyage, his survivors are careful to equip him with all the necessary material objects' (van Gennep 1960: 154). Enabling the deceased to complete the journey to the world of the dead is the main aim of funeral rites, and most rituals are conducted during this transitional period.

Van Gennep also points out that 'the passage from one social position to another is identified with a *territorial passage*, such as the entrance into a village or a house, the movement from one room to another, or the crossing of street and squares.' 'In short, a change of social categories involves a change of residence, and this fact I expressed by the rites of passage in their various forms' (ibid.: 192).

Van Gennep emphasizes the importance of the transitional phase of ritual, while his concept of the transitional period is never separated from the notion of separation and incorporation (Metcalf and Huntington 1991: 33). By contrast, Turner focuses almost exclusively on van Gennep's notion of the transitional phase, which sometimes acquires a degree of autonomy from the rest of the ritual. Turner develops a view of 'a state of transition'(Turner 1967: 94) and the notion of 'liminal *personae*' who are 'betwixt and between' 'the positions assigned and arrayed by law, custom, convention and ceremonial' (Turner 1969: 95). He further contends that 'the subject of passage ritual is, in the liminal period, structurally, if not physically, 'invisible'' (Turner 1967: 95). Hence these transitional-beings or 'liminal *personae*' are structurally indefinable and unclear[1]. Building on Mary Douglas's (1966) insight that the concept of pollution is a reaction brought into existence in order to protect cherished principles and categories from contradiction, and that what is unclear and contradictory tends to be regarded as (ritually) unclean, Turner postulates that transitional-beings or liminal *personae* are particularly polluting (Turner 1967: 97). He continues that:

> Since neophytes are not only structurally 'invisible' (though physically visible) and ritually polluting, they are very commonly secluded, partially or completely, from the realm of culturally defined and ordered states and statuses.
>
> (Turner: 1967: 98)

Turner also mentions the social structure of the liminal period, which is characterized by complete equality among neophytes (liminal *personae*), and complete submission of neophytes to the instructors of the ritual. He calls this social

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[1] For example, during a male puberty rite, a novice is neither a boy nor a man, yet a society's day-to-day definitions do not allow for the existence of such a (non-) person.

relationship *communitas,* which consists of equal individuals submitting together to the general authority of the ritual elders (Turner 1969: 96). According to Turner (1969: 95), liminal entities are totally under the control of the instructors of the ritual. 'Their behaviour is normally passive or humble; they must obey their instructors implicitly, and accept arbitrary punishment without complaint' (1969: 95).

Robert Hertz also focuses on the transitional period, yet his special concern is with death rituals, particularly the custom of secondary burials. Hertz's classic treatise, *Death and the Right Hand* (1960), sees the opposition of life and death as part of a wider social classification of parallel oppositions, and stresses the significance of liminality between them. As shown in his analysis of secondary burials in Indonesia, death is not necessarily viewed as instantaneous. In Borneo, for instance, it is seen as a process whereby the deceased is slowly transferred from the land of the living into the land of the dead. The person first dies biologically, but his non-physical soul is regarded as being in a state of limbo (which Hertz calls 'the intermediary period'), during which he is considered neither alive nor finally dead. The soul of the dead is thought to be homeless, hostile, and the object of dread. Various rituals are carried out in order to suppress the dangerous power of the soul, and it is believed that social death is confirmed only when the soul's arrival in the world of the dead is announced. This is the function of the secondary burial.

Hertz points out that there is a kind of symmetry or parallelism between the condition of the body and that of the soul; namely, until the body completes the process of decomposition, and enters its final tomb, the soul will not be properly admitted into the land of the dead. However, he also argues that it is not necessary in every case to observe the period of waiting until the body is decomposed into mere bones. Even in the very societies where the custom of secondary burial is

predominant, certain categories of people are purposely excluded from the normal funeral ritual. 'The death of a stranger, a slave, or a child will go almost unnoticed; it will arouse no emotion, occasion no ritual' (Hertz 1960: 76). However, 'at the death of a chief, or of a man of high rank, a true panic sweeps over the group' (ibid.). As Metcalf and Huntington (1991: 80) note, this distinction is explicitly sociological, as it turns upon the social status of the deceased. Hertz continues:

> Death does not confine itself to ending the visible bodily life of an individual; it also destroys the social being grafted upon the physical individual and to whom the collective consciousness attributed great dignity and importance. The society of which that individual was a member formed him by means of true rites of consecration, and has put to work energies proportionate to the social status of the deceased [...]
>
> (Hertz 1960: 77)

The intermediary period seems to repair the social disorder caused by an individual's death.

2. Social and biological death

Hertz's understanding of secondary burials therefore identifies the biological and social as two distinct dimensions or types of death, one terminating the human organism, and the other ending the person's social identity. Between these two there is an intermediary period, which varies from days to even years, depending on the society. Social death 'takes place at a series of ceremonies, including the funeral, whereby the society bids farewell to one of its members, and reasserts its continuity without him' (Helman 1994: 233). But this may take place a considerable time after the biological death. Some cultures do not consider the mere termination of physical

life as 'death' at all, even though the corpse may have started to decompose (Namihira 1996).

2.1. Termination of life within the social context

In the next section I will give a couple of examples of secondary burials between biological death and social death reported by Yamashita (1988) and Metcalf and Huntington (1991) followed by three examples of a reverse case when social death occurs prior to biological death.

2.1.1. The Toraja

Yamashita (1988, cited in Namihira 1996) presents the Toraja of Sulawesi in Indonesia as an example of this phenomenon. Yamashita's observations in 1977 on the death of a middle-aged common woman, who was married to a member of the Royal Family, are as follows:

> June – She died at her daughter's place. The body was purified with water immediately after death, and wrapped with a brand new cloth. It was situated with its head toward the west, and the basket containing some leaves and fruit which were usually placed for the ill was put beside the body (she was still called 'a hot person (an ill person)').
> October 15 – Building of a cabin for an altar was commenced at the woman's parents' home. The body was repositioned with the head towards the south, and the body was first recognized as 'dead'. The close kin had entered the mourning period.
> November 14th – The day called 'losing breath'. The dead body was transferred from the daughter's place to the woman's parents' place, and placed in the alter cabin.
> November 17 – The day called 'wrapping (the dead body)'.

> January 21 – The day of the funeral. The dead body was placed in the front garden, and offerings were put in front of it. The body was carried and laid out in a tomb which was six or seven hundred metres away from the altar.
>
> (Namihira 1996: 192-193)

For the Toraja, the termination of physical function is a necessary but not sufficient condition of death. Death can only be confirmed during the process of the mortuary ritual, and the termination of an individual as a part of the society does not happen until then. Namihira (1996) points out that the body is transferred from the daughter's house to the woman's parents' house on the day of 'losing breath'. The body is not recognized as dead until the preparation for this ritual is completed. It is this ritual that produces death, and the individual's death is established by the ritual process (Namihira 1996), not by the mere physical condition.

2.1.2. The Berawan

Metcalf and Huntington (1991) provide the example of the Berawan of Borneo, who have two major ceremonies. Each of these lasts several days and involves many people. The two ceremonies are separated by a period of at least eight months, and sometimes as much as five years. The first ceremony commences immediately after death. The corpse is displayed on a specially built seat for a day or two, and after all the close kin have visited it, it is placed in a coffin. At the end of a period lasting between four to ten days the corpse is removed for temporary storage. When the time comes to conduct the second ceremony, guests living far afield are summoned to attend. The bones of the deceased are cleaned and stored in a jar of smaller size. The ceremony lasts ten days, and every evening there is a boisterous party. Then the bones are transferred to their final resting-place. The reason behind

this long and elaborate ritual is to escort the enduring spiritual component of the deceased to the land of the dead:

> The soul of a sick person wanders from the body of its owner. Prolonged absence causes serious illness, but the soul may wander far, into spirit worlds unknown to humans, without fatal results. Only if it should enter the land of the dead by some devious route will death ensue. Then the minimal connection of body and soul is severed and the lifeless body begins to decompose. The soul does not stay in the land of the dead; it continues to wander.
>
> (Metcalf and Huntington 1991: 89)

The soul cannot re-enter the body after death, as putrescence would have already begun. If it did, a monster would result. In addition, the soul could not easily find its way back to the land of the dead, as it arrived there by accident, and even if it could find its way, it would not be accepted, as it would not yet have transformed into a good spirit. The main purpose of the secondary ritual is to instruct the soul to formally enter the land of death. During the secondary ritual, death songs are sung, firstly to 'pull' the homeless soul back, secondly to prepare it for the journey, and finally to instruct it to enter the land of death. Following the songs, 'the bones are taken to their final resting place in the monument prepared for them' (Metcalf and Huntington 1991: 87). Here again, death is considered to occur only when the soul arrives at the land of the dead and is welcomed by its community; therefore, as in the case of the Toraja, the Berawan believe that mere physical demise is not a sufficient condition to identify death. In other words, the termination of an individual is not considered to have occurred when the vital signs have disappeared. Termination only occurs through the process of ritual.

Metcalf and Huntington (1991) also point out that the fate of the soul is related to the fate of the corpse. When the body has begun to decompose, the soulless corpse

is considered a source of intense danger, and the homeless soul is also thought to be miserable and malicious. At night a large number of people get together near the coffin to talk, drink, and play games, and, officially, no adult should sleep at night during such funerals. This ritual serves primarily to entertain the soul of the dead person. It is also thought that the noise of the crowd and the bright lights burning all night would discourage the intrusion of evil spirits. The vigil is believed to prevent harm from befalling the corpse. The malicious soul needs time to convert itself into a spirit worthy of the land of the dead, just as the corpse needs time to become sacred bony relics. For the Berawan, who believe that death only occurs when the soul has successfully reached the land of the dead and the corpse become dry bones, even the decomposition of the body is not considered a sufficient indication of death. Death is declared only when the secondary ritual is accomplished.

It is also obvious that the secondary ritual is not conducted for the purpose of reviving the dead person. In support of this account, the Berawan believe that if the soul returned to the dead body a monster would result. The practice of calling back the soul of the dead person on the first night of the ceremony (which in fact may last as long as several nights) is to ensure that it is not wandering in some distant spirit world, and not an attempt to revive the person. The secondary ritual implies that while the group is in deep sorrow at losing an individual, it does not want the soul to have a deep attachment to this world forever. Additionally, it is presumed that the Berawan fear the body and the soul of the dead, and the main purpose of the ritual seems to be to appease the vindictive and miserable soul, to prevent the corpse from being reanimated, and finally to send the soul to the land of the dead. In sending the soul to that land, death is considered complete. It is only then that the soul is in a perfect enough form to be regenerated back into the world. As Namihira (1996: 213) remarks,

here the completion of death is also the beginning of regeneration, since only the soul that has reached the land of the dead becomes perfected and, subsequently, regenerated.

2.2. Social death prior to biological death

As shown above, normally biological death is presumed to precede social death; however, the reverse may sometimes occur:

> Here, individuals are still alive physically, but in a subtle way less alive 'socially' – in the eyes of the wider society, and sometimes their own families. For example, those who have been confined to institutions for the rest of their lives – prisons, old age homes, geriatric wards, hospices for the terminally ill, homes for the mentally handicapped – may all be said to have undergone a form of 'social death', long before the date of their 'biological death'. In many societies, retirement or unemployment may also have the same effect, as may the diagnosis of a serious disease, such as AIDS or cancer.
>
> (Helman 1994: 236)

In modern societies[2], the pattern of death and dying is different from that in so-called traditional societies. While people living in societies with advanced medical technology live longer, their very longevity makes them more susceptible in later life to disablement or infirmity as a result of accident or degenerative and incurable disease, the most prevalent being cancer. When an illness is diagnosed as cancer, the person will be often removed from his or her normal social life. Then, he or she may experience rituals of admission to a hospital or hospice where various medical treatments will be undertaken. This stage can be seen as a liminal, transitional, or

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[2] The distinction between modern and traditional society is made here in the context of the relative diffusion of Western medicine.

intermediary period. A patient will experience various customs for a variable spell of time. After this stage of transition, the person, whatever his or her condition, will go through rituals of discharge from the hospital. He or she is then either returned to normal society as a cured, healthy person who has overcome the cancer or, having died from their illness, made subject to funeral rituals. In this latter case, of course, the third stage is marked by whatever status is given to death (perhaps entry into another world), rather than by a status (e.g., as a cured patient living perhaps on borrowed time) indicating social re-entry into the present world.

Not surprisingly, many cancer patients I met during my fieldwork in Japan said that the diagnosis had changed their life completely. Once they were admitted to a hospital or hospice, the majority of them said that they did not want to see anybody apart from their family members. Some were ashamed of how they looked, which was completely different from when they had been healthy. Others lamented their uselessness as a member of society or of a family. Such resigned and self-deprecating attitudes on the part of cancer patients, not all of whom in fact suffer from terminal cancer, causes a kind of social death prior, and in some cases quite distant from, biological death[3].

In some of the societies examined by Bloch and Parry (1982), this idea of social death preceding physical death is made quite explicit:

> After the Lugbara [in Uganda] has said his last words to his heir, the latter emerges form the hut in which they have been closeted and calls out the *cere* – the personal chant – of the dying man, an appropriation which would be unthinkably evil at other times. This marks the moment of succession; and even if the patient lingers on after it, he is socially dead and his mortuary rites are performed as if he were dead.

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[3] The process of social dying at the PCU will be discussed further in chapter 5.

An even more extreme example is provided by the Dogon [of West Africa] (Paulme 1940) where in some cases funerary rites are performed for people who are presumed to be, but in fact are not, dead. When this occurs, and the 'dead' man returns, not even his closest kin will recognise him and he is forced to remain a nameless beggar until his physiological death.

The Hindu ascetic, who performs his own funerary rites at the time of his initiation, henceforth exists in the world as a wandering ghost, and his corpse is not cremated but simply immersed in the Ganges. The effigy of a missing person who is presumed dead will be cremated, and his subsequent mortuary rituals performed. If he then reappears and (in theory) nobody at all will eat with him, he does so as an intrusive ghost who has no place in the world of the living.

(Bloch and Parry 1982: 13)

According to Bloch and Parry (1982), in some societies the most threatening quality of death is the aleatory or random nature of its occurrence. The examples just given indicate efforts to control the contingency of physical death by making it accord with social death, that is to say, by creating a category of the socially dead, and treating these as already biologically dead and as absent in the world of the living.

2.2.1. Death by suggestion

Another common example of the social preceding the physical is death by suggestion. Marcel Mauss (1979) famously introduces various examples of such deaths from Australia, New Zealand and Polynesia. According to Mauss, among the Australians, moral and religious forces can cause death by suggestion. For example, an individual who has taken something forbidden (violation of taboo), or an individual who believes he is bewitched will die shortly after this fact is

acknowledged. In New Zealand, Mauss reports that deaths by magic and deaths following an omen are also very frequent. Once an individual finds out that he is bewitched, he passively accepts death without fighting it. The victim's friends also do nothing for him, equally accepting his fate. In this situation, the dying is treated as if he was already dead, and the dying individual accepts the situation. It can be said that the victim dies socially before his physical death.

This kind of treatment of death is also seen in the case of 'voodoo' death among aborigines of East Arnhem in Australia. In Arnhem, once a person discovers and believes firmly that he has had a curse placed on him, not only he, but his family members as well, fall into a critical situation, becoming obsessed with the idea that death is unavoidably imminent, and losing all will and vigour to remove this possibility. The person believing himself to be cursed braces himself for death, however healthy he may otherwise be, and allegedly does finally die. There seems to be some general convergence of views among physiologists and doctors as to the cause of this kind of death[4]. However, the anthropologist Gilbert Lewis (1977) points out that most of the accounts:

> [...] were hearsay stories, few of the cases were seen by those who reported them, all were unsupported by adequate medical investigation. Of course, it would require very special circumstances to be able to provide such information. But I stress this caution because there seems a readiness to accept such accounts as evidence when they come from exotic places, although they might not be taken with the same respect at home.
>
> (Lewis 1977: 136)

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[4] Cannon (1942), a physiologist, argued that voodoo death was caused by overexcitation of the sympathico-adrenal system as a result of stress caused by fear of sorcery. Lex (1974) also gives a physiologically based interpretation, employing the notion of 'tuning' the human nervous system.

Bearing in mind criticisms of the type that Lewis has made regarding past studies of voodoo death, the psychiatrist Harry D. Eastwell (1982) has carried out research and collected data since 1969 during visits that were primarily for the purpose of conducting psychiatric clinics among Aboriginal people. The data were compiled from patients' medical records kept at bush hospitals and outstation clinics, and from Aboriginal health workers. From this investigation, Eastwell concludes that the basic physical process of dehydration is the direct cause of voodoo death, health workers having reported that fluid is intentionally withheld from the victim in order to accelerate his or her death. According to Eastwell (1982), people living near the person who is convinced that he or she is cursed begin to treat the cursed as dead, leave him or her alone, and actually encourage him or her to die as soon and as smoothly as possible by chanting funeral songs, instead of seeking a cure. Once believed cursed by others, the social termination of the individual within a society ensues. The cursed ceases to be regarded as a living person and is neglected and in effect abandoned by the community. The victim is supposed to play the role expected of him or her in this process, namely, to accept death and reject nourishment, fluid and medical aid. As Eastwell puts it:

> The ideology of clanship in Arnhem includes the concept of recycling the individual soul through future generations of the clan. This implies a quality of timelessness to individual life which aids the acceptance of death [...] terminal patients often show great relief once the rites have began [...]
>
> (Eastwell 1982: 13)

For people in Arnhem, isolating the victim without giving him or her any fluid seems to be regarded as the means to a desired premature death. Voodoo death, which

seemingly occurs against the living's wish, is actually caused by intentional actions taken by the living who encourage the cursed to die as smoothly as possible.

2.2.2. Leprosy patients

'Leprosy is a chronic communicable disease of the skin, eyes, internal organs, peripheral nerves, and mucous membranes' (Gussow and Tracy 1977: 396). Since it produces severe physical handicaps and disfigurement, the disease has carried an onerous burden of stigma, and the victim of leprosy has been transformed into a social outcast in many parts of the world.

In Japan, for example, leprosy patients were removed from society, and suffered from discrimination and isolation until they finally died at a leprosarium, where they had usually spent all of their life since the diagnosis. This was the case until the Leprosy Prevention Act (established in 1953) was abolished in 1996.

Leprosy was called *tenkei-byō* (a disease as a punishment from Heaven) or *gō-byō* (a disease caused by evildoings in one's previous life) in Japanese (Okiura 2001: vii). This public view of leprosy already prevailed throughout Japan during the Edo period (1603-1868). At that time, leprosy was misunderstood as a genetic disease which passes on to the next generation, and this is why it was called *tenkei-byō* or *gō-byō*. This classification of the disease resulted in leprosy patients being driven to despair, with some taking their life when their human dignity had been taken away from them (Okiura 2001: vii). In 1873, a Norwegian doctor, Hansen, discovered that bacteria caused leprosy, and in 1897, it was medically accepted at an international conference in Berlin that leprosy was not a genetic but an infectious disease. This fact, however, resulted in the Japanese government's policy to isolate leprosy patients even further.

The public tendency towards discrimination and isolation of leprosy patients and their families could still be observed after the Second World War in Japan. Once found to be suffering from leprosy, not only the victim but their family as well fell into a critical situation. Typically, members of the family with a leprosy patient were dismissed by the community, and marriage alliances cancelled. Therefore, for their family's sake, many leprosy victims accepted their fate of being sent to a leprosarium, where they would spend the rest of their life, and attempted to disappear from the public eye. The family also gave them up in order to avoid the social discrimination and isolation caused by leprosy[5].

The Japanese counsellor for discrimination, Chikara Hayashi, whose father was sent to a leprosarium in 1937 and spent his life there until his death in 1962, notes that the only one wish which his father had was 'to hide' himself away. The following is what Hayashi's father wrote to Hayashi in a letter dated 1 April 1954.

> [The existence of] your father is your lifetime secret. You should keep this as an iron rule and live on. The only thing your father asks you is this. Please do not forget.
>
> (Hayashi 2001: 255)

Hayashi also mentions that:

> In the situation where all [leprosy patients] used a false name, the majority abandoned their hometown, and were also abandoned by their hometown, my father repeated not only in his letters, but also whenever I visited him at the leprosarium, 'I often hear stories of families who fell into extreme distress, when found out that they have a leper in the family. Chikara, your father's existence should never be known by anyone.'
>
> (Hayashi 2001: 255)

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[5] Richie (1971 [2002]) describes that once sent to a leprosarium there was no hope to return to society even if a sufferer was cured. This was because the sufferer's name was removed from the family register at the point of

While Hayashi's father tried to disappear from society, Hayashi also tried to forget him:

> [...] sweet memories of my father soon became the subject of dread, and I frankly have to tell you that I could not stand him. I really hated the fact that my father was alive in that world. I wished he had been dead, so that I could have hidden the fact [that he had a father with leprosy].
>
> (Hayashi 2001: 249)

Most leprosy patients and their families at that time went through similar experiences. With the progress of the disease, the appearance of the patient worsened. This distressing process encouraged the public to regard patients as an impure entity, which should be avoided, removed and isolated from society. The patients' families even hoped that the patients would die and soon disappear from society; otherwise, they would become the subject of discrimination and be removed from society themselves. Patients also hoped to die soon for the sake of their family. Patients were usually confined within an asylum-like leprosarium, being isolated from their family and hometown. Many of them had little chance to see their family again before they died. They also abandoned their real names in order to hide themselves from society. Patients were not given rights to receive appropriate treatments at the leprosarium, and they were also deprived of their ability to reproduce. Regardless of their hopes for marriage, most were arbitrarily sterilized (Endō 2001: 156-157; Fujino 2001: 60), and pregnant patients were forced to have an abortion (Yomiuri On-Line 2001).

The Japanese historian of medicine, Shōji Tatsukawa, describes leprosy as the most miserable disease in the world. He continues that:

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being sent to a leprosarium, and the sufferer was treated as though he or she had never existed in society.

> [Leprosy] is a chronic disease which progresses extremely slow; therefore, patients have to live and spend a long period in great misery until death. Leprosy is not strongly contagious at all; in fact it is much less so than tuberculosis. Why did societies show this severe reaction to the disease? One of the major reasons is explained by its visible symptoms. A part of the body gets gradually rotten, and the odour emitted by the diseased parts and the fact that those who have serious symptoms have a horrifying look resulted in the serious reaction by the public against leprosy. The thin and worn-out body of tuberculosis patients brings about sympathy; however, the body of those who suffer from skin disease brings about repulsion.
>
> (Tatsukawa 1971: 51)

Probably due to the terrifying symptoms shown on the surface of the body, leprosy was the most immense subject of hatred compared to any other disease. Therefore, as shown above, until recently leprosy patients were to be removed from society regardless of their will and they even hoped to die as soon as possible.[6] Patients had to abandon their past social existence (i.e., by using a false name and being secluded from their hometown and family), and they were often treated as a person who was already dead by their family and the public. Tamio Hōjō, who was a leprosy patient, said in his essay '*Inochi no Shoya* (The first night of life)' that one dies at the moment of being diagnosed with leprosy (Yamamoto 1996: 110). In other words, leprosy patients died socially at the time of their diagnosis, and had to live as dead or as a non-person until physical death occurred. Although the individual did not change as a person, the diagnosis would make the society regard the patient as totally

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[6] With the development of a specific medicine for leprosy in 1943 in the United Sates, segregation of the patients was ceased and more open outpatient treatments were developed in the West. On the other hand, despite the introduction of the new medicine, leprosy patients kept suffering an absolute forced segregation in Japan (Namase 2001).

different. Living with this incongruity between one's self-identity and social identity is an additional a cause of fear for the patient (Gussow and Tracy 1977: 398).

2.2.3. Chronic illness

The Tabwa of Zaire call people who are chronically ill, and who suffer repeated episodes of severe illness followed by partial remission *wabovu*, which literally means 'rotten' or 'unsound' (Davis 2000).

The sick person is indeed looked after by household members. The family go from one practitioner to the next seeking a cure for the patient's illness; however, if the condition persists, the patient's illness may exhaust both people and resources. The family will then stop to spend time and money seeking a cure of the patient's illness. The condition of chronic ill health is considered hopeless, and kin and even the patient him/herself regard the person as 'just meat' and give up on him/her (Davis 2000). While minor illness indicates the proximity of *mizimu* (the dead antecedents) to the sick person, the condition of chronic ill health is considered that an ill person has been abandoned by his spirits or has been marked by sorcery. 'The taintedness of this state is indicated by the idea that, when in it, a person has been hobbled like a goat by the sorcerers, who intend to make of him their meat. Such a person is thus doomed to die and be eaten by them no matter what he does or where he goes' (Davis 2000: 242).

2.2.4. Social death in modern society

A common feature of the examples of social death illustrated above is that, unlike comparable examples in modern society treated, say, through psychotherapy,

none of those who are recognised socially dead are encouraged to live. On the contrary, they are actually discouraged from doing so and are regarded and treated as dying or dead already, with the socially dead accepting this social judgement and responding through behaviour that helps them on to physical death. It is perhaps this question of whether or not the dying are encouraged to live which constitutes the greatest difference between traditional societies and the contemporary dying process with regard to ideas about social death preceding biological death.

In contemporary societies, cancer patients, for example, are encouraged to live until their last day, although they are aware of their impending death. Therefore, although a kind of social death does occur before biological death (i.e., abandoning one's social identity at admission to a palliative care unit), the individual is nevertheless expected to *live* as best as he or she can, with the family encouraging him or her to do so. The encouragement given to dying patients to live as actively as possible is considered to result in a 'good death', as distinct from a 'bad death' in which the patient has fallen into social death (i.e., the patient becomes a non-person) long before physical death occurs[7].

In the following sections, I will look at so-called traditional societies, and briefly examine some of the death rituals conducted during the intermediary period, followed by an examination of the concepts of 'bad death' and 'good death'. Then I will turn my eye on more modern societies, and will investigate how the concept of a modern 'desirable death' or 'good death' has been developed.

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[7] In many societies, bad death is considered to occur when the deceased has been suddenly and often violently taken before his or her time, often through accident or war. Both a too sudden death and a too prolonged death (which results in a large gap between social and biological death) are regarded as bad deaths. 'Desirable death' or 'good death' is perhaps normally unmarked in most societies (in contrast to bad death) but in the modern hospice movement this is an explicit aim.

3. The intermediary period and death rituals

The focus of death rituals in many societies is on the 'transitional period', 'intermediary period', or 'liminal period' which highlights the distinction or transition between organic and social death. Usually this period is from the moment of physical death to the formal cessation of mourning; in many societies the pollution of death is regarded as most virulent throughout this period, and the corpse as the subject of dread and revulsion.

3.1. The body, the soul and the living

Hertz (1960) explored the complexity of death rituals and the origin of the horror that surrounds the corpse using three different *dramatis personae*: the corpse, the soul, and the mourners. Metcalf and Huntington (1991) illustrate the relationship between the three in the shape of a triangle, the corners of which relate to the corpse and the burial, the soul and the dead, and the living and the mourners (see Figure 1). Hertz employs the relation of each element to others in order to answer the deceptively simple questions: Why is the corpse feared? What is the origin of the horror that surrounds it (Metcalf and Huntington: 1991)?

Hertz points out that 'we must not attribute to these people feelings and scruples about smell which are foreign to them' (1960: 32), and that 'the horror inspired by the corpse does not spring from the simple observation of the changes that occur in the body' (1960: 76). He rejects at the outset any explanation that relies on natural disgust; instead, he offers a more sociological argument: the magnitude of fear felt by the living depends on the social status of the deceased. 'At the death of a chief, or a man of high rank, a true panic sweeps over the group. [...] On the contrary, the

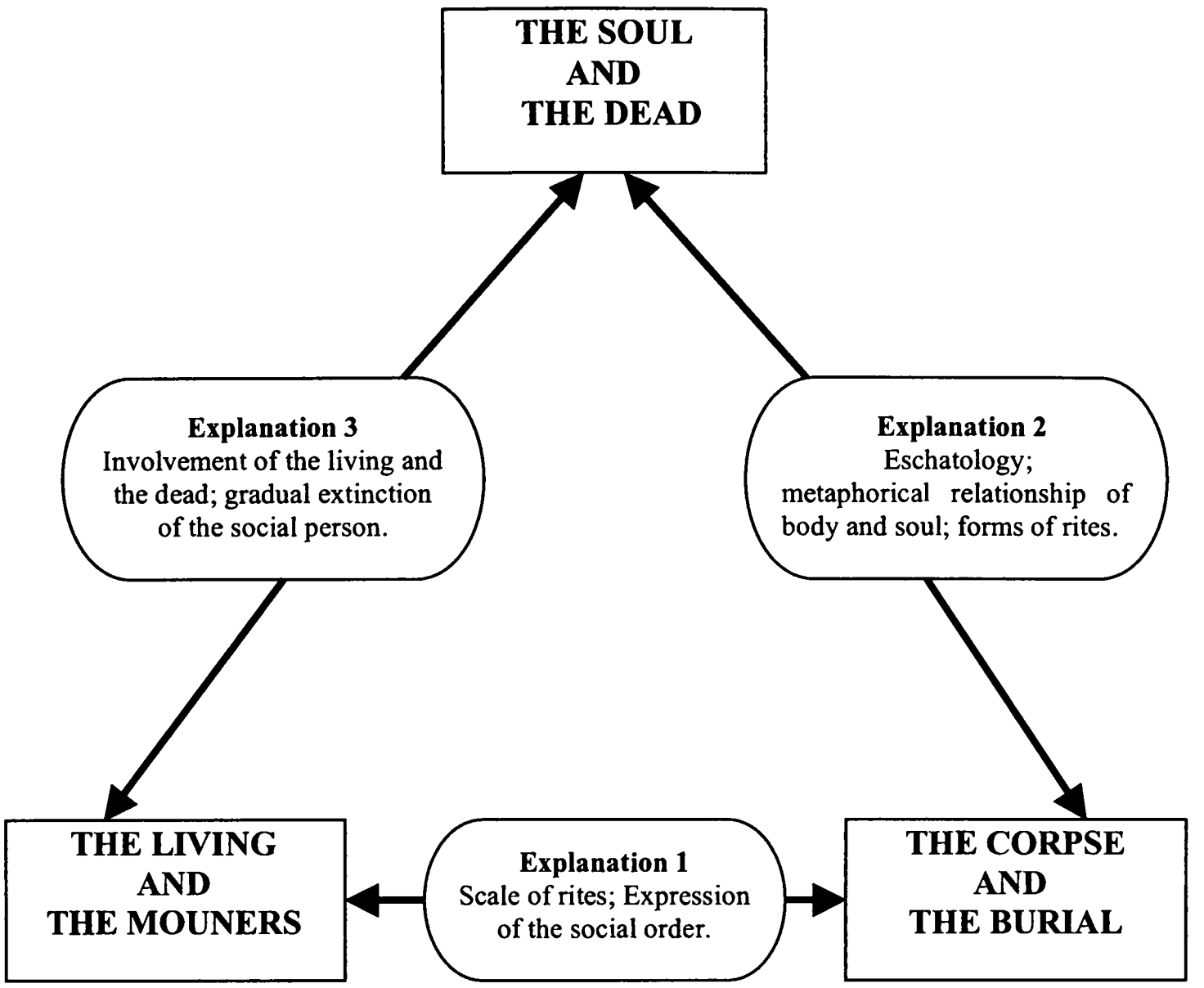

Figure 1. Schematic diagram of Hertz's arguments: Metcalf and Huntington, *Celebrations of Death* (Cambridge, Cambridge University Press, 1991), 83.

death of a stranger, a slave, or a child will go almost unnoticed' (1960: 76). The death of an influential person presents a consequential problem to society; therefore, it is regarded as the subject of fear (Explanation 1).

Hertz also gives an explanation which relates the fate of the soul to the body (Explanation 2). From Indonesian sources, Hertz demonstrates 'a kind of symmetry or parallelism between the condition of the body, [...] and the condition of the soul' (1960: 45). In other words, the soul of the deceased is thought to remain with the living until the decomposition of the corpse is complete. Hertz offers the example of the Botocudo, who believe that 'the soul remains in the neighbourhood of the tomb till the decomposition is completed' (1960: 46). During this period, the living are afraid of approaching the tomb. The soul of the deceased, which is mobile and relatively independent, is believed to be malicious and harmful to the living until the corpse turns into mere bones, and this is why the corpse is feared.

Hertz also explains the fear associated with death in relation to the soul and the living (Explanation 3). Here he demonstrates that the intensity of fear among the living is engendered from the extinction of the social person:

> As long as the temporary burial of the corpse lasts the deceased continues to belong more or less exclusively to the world he has just left. To the living falls the duty of providing for him: twice a day till the final ceremony, the Olo Maanyan bring him his usual meal; [...]. During the whole of this period the deceased is looked upon as having not yet completely ended his earthy existence [...] in Timor, when a Rajah dies, his successor cannot be officially named until the corpse has had its final burial; for until that burial the deceased is not truly dead, he is simply "asleep in his house".
>
> (Hertz 1960: 36)

The demise of a social person is feared by members of society, especially if the person is notable and influential. The extinction of the social person is associated with the absolute dissolution of a corpse, and hence with the state of the soul of the deceased. This explanation appears at first sight to be a statement about the corpse; however, in reality it relates the soul (in the form of the memory of the dead) to the living (Metcalf and Huntington 1991: 82).

During the intermediary period, the body, the soul and the living are interrelated to each other, and each aspect of this interrelationship explains why the dead body is feared by the living. The fear is not simply explained by the visible process of decomposition itself. The intensity of fear felt by the living depends on the social status of the deceased, and this derives from the fading of a social person and the absolute dissolution of a corpse. Between the condition of the body and that of the soul a kind of symmetry or parallelism is considered to exist. The soul of the deceased is feared by the living because a soul is thought to remain with the living until the decomposition of the corpse is complete, and until then it is capable of inflicting harm. The body which reflects the condition of the soul is thus also feared during this period. The visible process of decomposition alone, therefore, does not explain the fear which is shown by the living.

Moreover, each relationship can be utilized to account for different aspects of the funeral rite (such as the reason why the scale of the funeral varies) and the meaning of the mortuary rituals and the treatment of the corpse.

4. The concept of bad death and good death

4.1. Death and continuity

Before discussing particular forms of death, such as good or bad deaths, I would like to point out that there are societies which seem almost to ignore the dead, abandon them and have little to do with them. Woodburn (1996) discusses examples of such societies. He illustrates belief and practices associated with death in four African hunting-and-gathering societies – the Hadza of Northern Tanzania, the net-hunting Mbuti Pygmies of Zaire, the Baka Pygmies of Cameroon and the !Kung Bushmen in Botswana and Namibia. Woodburn summarizes the similarities between these societies as follows:

(1) The actual procedures for treatment of and disposal of the body are relatively simple and mundane.

(2) The various tasks and responsibilities connected with the burial or disposal of the corpse and with other procedures which follow death are apparently not in general allocated to specific kinsmen and affines.

(3) There is no clearly defined distinction between a good and a bad death.

(4) There is no search for the cause of death.

(5) There may or may not be a belief in an afterlife.

(6) After the practicalities of the immediate ceremony (if any is performed at death) ordinary life goes on. There are minimal rules for mourners or other survivors. There is no clear marking out of the widow or widower and no rules restricting the timing of remarriage or whom they may remarry.

(7) There are no chiefs, shamans or other specialists whose special task is to administer or control death rituals.

(8) Death procedures are only peripherally connected with ideas relating to fertility of human beings or of plants and animals or of the natural world more generally.

Although he admits to the selectiveness of his data[8], Woodburn attributes the above similarities to a shared social organization, which he defines as an 'immediate-return system'. According to him, there are two basic kinds of social system, based on 'immediate-return' and 'delayed-return economies'. The former is:

> One in which activity oriented directly to the present (rather than to the past or the future) is stressed, in which people use their labour to obtain food and other resources which are consumed on the day they are obtained or casually over the days that follow, in which there is a minimum of investment in long-lasting artefact or in long-enduring debts, obligations or other binding commitments to specific kinsmen, affines, contractual partners or to members of bounded corporate groups, however these are recruited.
>
> (Woodburn 1996: 295)

The other kind of social system—delayed-return economies—can be seen in the vast majority of human societies, even many hunting-and-gathering societies, and displays the following characteristics:

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[8] Woodburn (1996: 202) points out that in these African societies, human death is relatively invisible in comparison with societies whose members live in much larger communities and at much higher population densities. Thus, only a small number of instances have been observed and most have been hearsay stories, whose accuracy may be affected by the sensitivity of the topic.

> People hold rights over valued assets of some sort, which either represent a yield, a return for labour applied over time or, if not, are held and managed in a way which resembles and has similar social implications to delayed yields on labour.
>
> (Woodburn 1982: 432)

Woodburn points out that 'the death beliefs and practices of these four societies are ones which stress personal, temporary grief, and the temporary shared grief of the wider food-sharing community undifferentiated except by age and sex. There is no emphasis at all on dependence between specific kin or affines, or their moral responsibilities to each other' (Woodburn 1996: 206). He further explains that the limited death beliefs and practices result from the scarcity of notions of succession and inheritance in these societies, since 'there is no office of household head, nor any other office of much significance nor any property of much value, to be transmitted from one generation to the next. When someone dies, he is not *replaced* socially by someone else in the sense that he or she is in delayed-return systems' (Woodburn 1996: 206). Death has a lesser impact upon an immediate-return society. The meaning of social death is much less significant.

According to this explanation, people of the four societies examined by Woodburn do not regard death as a threat to their society. Since these societies do not stress the idea of social continuity, and death is largely a matter of personal feeling, it does not threaten the social value or system, and hence the ideological elaboration of death beliefs and practices in general is not as developed.

According to Namihira (1996), the opposite applies in Bloch's analysis of the Merina of Madagascar:

> Some societies develop their mortuary rituals, while others do not. Mortuary rituals are not always developed because people elaborate the concept of the afterlife, but because they regard discontinuity caused by an individual's death as a menace to their society, and consider that death will spoil the social value, authority, and system which should be maintained permanently. Mortuary rituals are performed in order to remove this menace.
>
> (Namihira 1996: 168)

To sum up, it has been suggested that the notion of continuity or intergenerational transmission accounts for the elaboration of mortuary rituals, and societies where this notion is absent tend to fail to provide a fertile ground for the ideological elaboration of death beliefs and practices in general, and vice versa. When considering bad and good death in many of those societies which have developed mortuary rituals, the notion of continuity is suggested to play an important part.

4.2. Examples of bad death and good death

Death through accidents and homicide are regarded as 'bad death', which refers to 'a human exit that was ill-timed and so failed to satisfy the normal expectations associated with natural death' (Metcalf 1982: 254-7, cited in Parkin 1985). If the 'normal expectation' is successful intergenerational transmission as discussed above, bad death can be assumed to be a death which interferes with the long-term continuity of the society, and good or normal death is a death which does not affect this.

According to Bloch and Parry (1982), for the Merina of Madagascar there is nothing worse than the possibility of losing the deceased one's body so that it cannot enter the communal tomb. 'The secondary burial of the corpse not only recharges the fertility of the descent group and its land, but also rescues the deceased himself from

complete obliteration. Therefore, without it [the body], a potential source of regeneration [hence long-term continuity of the society] is lost to the group, and the death of the individual is truly terminal' (Bloch and Parry 1982:15).

The Lugbara of Uganda believe that ideally a man should die at the correct time, in the correct place, and in the correct manner (Bloch and Parry 1982:142). Such a good death enables him to say his last words to his heir. In this way, the proper order of the lineage is maintained in the locality where the lineage is anchored and continuity is guaranteed by the smooth transfer of authority (Bloch and Parry 1982: 16). Additionally, in order to die a good death, the dying man should die physically when he is expected to do so, because he has said his last words. When physical and social deaths are reasonably congruent, it is considered that the person dies a good death. Middleton (1982:142) describes a good death for the Lugbara man as follows:

> A man should die in his hut, lying on his bed, with his brothers and sons around him to hear his last words; he should die with his mind still alert and should be able to speak clearly even if only softly; he should die peacefully and with dignity, without bodily discomfort or disturbance; he should die at the time that he has for some days foreseen as the time of his death so that his sons and brothers will be present; he should die loved and respected by his family. He should die physically when all these conditions have been or can be fulfilled and when he is expected to do so because he has said his last words and had them accepted by his kin and especially by his successor to his lineage status.
>
> (Middleton 1982:142)

On the contrary, 'a bad death takes place when the psychical elements of the person do not disperse properly and at the same time, or they do so at a wrong time or in a wrong place' (Middleton 1982:143). If death occurs 'outside' (neither at home nor at a sacred place), the soul of the deceased is believed to have difficulty in

returning to the ancestral shrines. Unforeseen and unexpected death is, therefore, considered bad. A bad death for Lugbara men includes death which has occurred outside, death through warfare, accident or homicide, and sudden death from witchcraft or sorcery.

For Lugbara women, on the other hand, the most common form of bad death is to die in childbirth. 'She is at the time surrounded by taboos that symbolically remove her hut from the remainder of the settlement in which it stands, and so she dies in the "bushland" just as though she were killed fighting outside in the bushland' (Middleton 1982: 144). A woman giving birth is like a man going to fight enemies, and both have their socially approved duties. 'She is also herself in a condition of transition and not a "normal" person' (ibid.). To die in childbirth also means that a woman fails to fulfil her social duty and that she also fails to contribute to the society's continuity. Being killed by witchcraft or sorcery are other common examples of bad death for women.

Sasaki (1996), who conducted research on bad death among the Ejagham, Southwestern Cameroon, reports that the judgement of good and bad death is based on the symptoms shown at the time of death, and the place where death occurred. Deaths caused by some particular symptoms and occurring in the bush, river, or the lake are all regarded as bad[9], and the body is buried in a very different manner from those who died normally[10]. Sasaki introduces various other examples of bad death from the Cross River Region where the Ejagham live. However, while there are a

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[9] Sakaki (1996) argues that bad deaths are attributed to the grudge that one has against someone in the society; it is said that an individual who has this ugly feeling will die a bad death in the end.

[10] When one dies normally, the body is cleaned with water and clothed in a clean white clothe. The body is surrounded by many flowers, too. After the funeral, the body is buried in the back yard of the deceased's house. Traditionally, the Ejagham even buried the body in the house. Sasaki (1996) assumes that this means that the deceased is still regarded as a member of the family and the living still feel close to the deceased. On the other hand, when a person dies a bad death, his tongue is cut off and his body is buried face down in the evil forest.

great many examples of bad death, Sasaki points out that very little is reported on good death. He continues that:

> Good death in the Ejagham society is the death which is not associated with *oje* (grudge), any diseases, and bad spirit. Good death occurs only when one dies from decrepitude within *etek* (their living space). The author has never witnessed such cases during his fieldwork, and all the Ejagham unanimously say that it [good death] is an extremely rare case.
>
> (Sasaki 1996: 17)

The influence of bad death on the society is stronger than that of good or normal death. Bad death is, therefore, more distinctly featured than other types of death.

In societies where long-term social continuity is significant, death which promises a rebirth for the individual and also a renewal of the world for the living is considered admirable. On the other hand, death which represents the loss of regenerative potential and the disturbance of the social continuity should be avoided. Death which is considered not properly completed and thus not perfectly prepared for regeneration, is perceived to be bad. In addition, in some societies where social continuity is less significant, there is no clearly defined distinction between a good and a bad death.

5. Summary

The examples of secondary death ritual demonstrate that in some societies, a person is not considered dead even when the body stops functioning (biological death). He is considered dead only when the soul is regarded to have reached the next world (social death). Conversely, there are also cases that social death occurs prior to

biological death (e.g., leprosy patients) In this case, the socially dead are treated as if they were already physically dead, and are discouraged to live by others, with the socially dead accepting this social judgement. The reason why the socially dead in traditional societies are treated as already dead, and encouraged to die physically soon is because the contingency of the occurrence of death is detested. It can also be because the ambiguous and polluting nature of the intermediary period between social and biological death threatens the living. By bringing forward the time for a biological death, the living can make the period between two kinds of death shorter, and can manage not to face the fear and threat caused by the intermediary period.

Another way to make the intermediary period shorter is to put social death off until biological death occurs. This case can be seen in contemporary societies, especially at hospices and PCUs, where cancer patients go through a kind of social death (i.e., abandoning the social identity) before the biological termination of life. At hospice and PCUs, the patients are encouraged to sustain their self and to live as active as possible until their final hour, so that they do not suffer from a social death long before a physical one. The way of dying at hospices and PCUs is unique in this sense as none of the examples from traditional societies and leprosy patients in Japan discussed earlier shows this kind of trend. Within the context of the hospice philosophy, however, a problem awaiting solution is how to withhold a social death from happening; namely, how the patients can sustain their self despite the fact that they suffer from rapid physical deterioration, and lose their autonomy. The hospice philosophy challenges several issues which no one has ever faced before.

Chapter 3: Japanese Death Rituals

In the previous chapter, we looked at death rituals in more traditional societies, where modern medicine does not prevail. Hertz's argument on secondary burials highlighted the fact that there are two kinds of death—social and biological death. The period between the two deaths (the intermediary period) is considered dangerous for the living. A funeral consisting of a series of rituals is carried out during this period in order to suppress the dangerous power of the soul.

Based on what I examined in the previous chapter, here I would like to discuss some detailed accounts of Japanese funeral rituals. First, traditional community funeral rites will be explored, since these rites used to display various elaborate rituals, and it is supposed that a close examination of each ritual will provide a base to understand Japanese attitudes towards death. Next I will consider contemporary Japanese funeral rites, and make a comparison between traditional and contemporary death rituals in Japan in order to investigate any historical change in attitudes towards death. The concepts of good and bad death in Japan will also be discussed, which helps to understand how the living perceive and treat death within a particular cultural context.

1. Death rituals in Japan

Although there are various religions practicing funerals in Japan, the majority of the rituals associated with death in Japan are carried out by Buddhist priests. According to Hendry (1995: 144), there are secular ceremonies, and there are Shinto rites for exclusively Shinto families, but by far the most common arrangement is to turn to Buddhism[1].

According to the Japanese ethnologist, Kōkyō Murakami (1990; 1997), dramatic changes took place in the way in which death rituals were observed during the Taishō period (1912-25) in Tokyo. Up until the end of Meiji (1816-1912) death rituals had a funeral procession as the main event. The development of public transportation during the Meiji and Taishō periods caused crowded streets in Tokyo, and this made it impossible to carry out large-scale funeral processions. At the same time, public transportation limited the number of people willing to join in a procession. Rather than taking part in the procession, people who were not directly related to the deceased began to take public transportation to join the funeral later on. Therefore, the number of people attending funeral processions decreased. Instead the funeral service itself began to take on more significance during the Taishō period. Along with this change, most of the funeral rituals which used to be conducted by relatives and the community started to be left to an undertaker. By the end of the Taishō period, modern crematoria and park-like cemeteries were also built and gained

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[1] During the Edo Era, the Tokugawa shogunate controlled Buddhism and used it for political means. The shogunate prevented Buddhism from connecting directly with people through social work and medical service, and forced Buddhist priests to be only engaged in funeral rituals or memorial services. This tendency is still seen in contemporary Japan (Nakura 1995: 31-32).

in popularity[2]. These changes were, however, observed only in limited areas, namely in some of the major cities, such as Tokyo, Osaka and Nagoya. It was not until the advancement of economic growth in the 1960s that death rituals in most parts of Japan began to be treated by undertakers (Yamada 1999: 103). Until that time, death rituals were still largely based around the community.

1.1. Traditional community death rituals in Japan

Traditional Buddhist death rituals usually consisted of the following stages: (1) occurrence of death and preparation for rituals; (2) wake; (3) funeral procession; (4) funeral; (5) burial; and (6) memorial service.

1.1.1. Occurrence of death

When a person was dying, the family member who sat closest would dip a bamboo chopstick wrapped with cotton on one end into water and wet the dying person's lips' (Suzuki 2000: 41) in order to give 'last water' (*matsugo no mizu*) in a final attempt to resurrect them. Namihira (1990: 57) notes that there used to be a ritual called *tamayobai* (literally 'calling the soul') in some parts of Japan. At the last moment of life, the immediate family members of the deceased climbed up on the roof of the house, and called out the name of the dead. A certain number of close

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[2] According to Tsuji (2002), cremation had been practiced in Japan since the sixth century. In 1873, however, cremation was prohibited by the Meiji government. This policy was part of the government's attempt to restore the indigenous Japanese way, as cremation was a custom associated with a foreign religion, Buddhism. Cremation at that time also caused lots of problems, such as the smoke and odour. In 1872, however, the government also banned the custom of burying a corpse at the edge of a cultivated field. This means that burying was also a common practice at that time. The ban on cremation lasted for only two years because of a strong protest movement by Buddhist priests and crematorium operators. Cremation was reinstated, yet it came with strict regulations. Crematoria needed to be properly equipped and located a good distance away from residential areas. This made it difficult to return to the old custom for some communities, and in many areas people maintained a burial practice. Tsuji (2002) reports that a village in Shiga Prefecture had switched from

relatives sometimes called out the name of the dead into a well[3]. Suzuki suggests that this ritual was performed because the living wanted to call to the dead person's soul to resuscitate the body. On the other hand, however, Namihira believes that the same ritual can be used to confirm death. To support this account, Namihira (1990: 58) indicates that *tamayobai* was sometimes performed after the body was tied up with a rope so that it could be placed in a coffin easily before rigor mortis set in[4]. Furthermore, the distancing displayed by fact that those who climbed up to the top of the roof had to put on special clothes (*kimono*) and a straw raincoat inside-out and upside-down respectively also shows that the person's spirit was not an acceptable entity even if it had come back to the body[5]. These acts reflect the belief that death was thought to happen when the spirit became detached from its owner. When the spirit did not return to the body, the person's physical death was confirmed. These acts, therefore, can be called the rite of confirmation of death, as well as that of resurrection.

When death was confirmed by the rites of confirmation of death, some rituals were performed 'to break the bonds between the deceased's spirit and its physical body so that the liberated spirit could safely depart for the world of the dead' (Suzuki 2000: 40). The deceased's face was turned upright or toward the west, and the mattress was turned so that the deceased's head faced north (Suzuki 2000: 41). A sickle, a pair of scissors or a mirror was placed on the chest of the dead in order to protect the dead body from a malevolent spirit called *kasha* (Namihira 1990: 60). Suzuki (2000: 41) also reports that in some areas a razor or a sword was used. In

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cremation to burial when the government outlawed cremation. The village, however, retained a burial practice until 1983 despite the reinstatement of cremation.

[3] Inokuchi (1977: 17) reports that this custom was observed all over Japan, from Aomori to Okinoerabu Island. The custom was called by different names in each area.

[4] Formerly, the corpse was doubled over to be placed in a coffin in an upright squatting posture.

others, a golden folded screen (*kin byōbu*) was erected upside down at the bedside. Whatever the object used, the purpose of the rite was to avoid the malevolent spirit entering the dead body. The spirit once departed from the body was considered malevolent, and it was not supposed to re-enter the body of the deceased. Namihira (1990: 60) also explains that there was a belief that the dead body had the power to attract an evil spirit which would cause bad luck or danger to living individuals. Clearly, a principle of inversion is stressed in preparation for and performance of the rituals. The aforementioned upside-down golden folded screen is such an example. This aimed at differentiating the period of death from the ordinary run of time (Saitō 1986: 29-81, cited in Suzuki 2000: 41). The following customs are further examples of inversion:

(1) The warm water used for cleansing the body is brought to bath temperature by first putting cold water into a vessel and then adding hot water (This is called inverted water [*sakasamizu*].).
(2) The *kimono* in which the body is dressed has its right lapel under its left (facing the body)[6]. (This is called 'left-in-front [*hidari-mae*]'.)
(3) The quilts that cover the body are placed with the pattern upside down.
(4) Home furnishings are placed in reversed positions, with blinds and screens upside-down and inside out and the rush mat, on which the body is placed, turned upside down.
(5) Whereas usually the soup is placed on the right and the rice bowl on the left, in the case of a funeral they are set the other way round. (This is called 'left table' [*hidari-zen*] or 'Ebisu [*Wealth God*] table' [*Ebisu-zen*].)

(Namihira 1987: 66)

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[5] This concept of inversion will be discussed later in this section.
[6] The *kimono* is normally worn right in front.

Before being placed in a coffin, the deceased's body had to be cleansed using *sakasamizu.* Only immediate family members, such as the deceased's offspring, brothers or sisters, were allowed to be involved in these activities, since otherwise death pollution would spread to other people (Shintani 1992; Murakami 1990: 39).

Even after these rituals, the spirit of the dead was not considered to have gone to the next world. It was outside the body, but still nearby. It may have been believed that if the spirit were treated as if it was alive, it would not go to the next world successfully, and it would possess the living. Thus inversion stands as a symbolic expression of the fact that death is the opposite of the normal or usual way (Namihira 1987: 66). This explains why the rituals of inversion were carried out at this stage—the spirit was encouraged not to stay in the normal world.

Hertz's study of the notion of secondary burial (1960) also illustrates a similar relationship between the corpse and a spirit which does not go instantly to the next world at the time of physical death. As Metcalf and Huntington explain:

> The fate of the corpse is to suffer putrescence and formlessness, until only dry bones remain, hard and imperishable. It was Hertz's insight that, in Borneo, the fate of the body is a model for the fate of the soul. As the corpse is formless and repulsive during the intermediary period, so the soul of the dead person is homeless and the object of dread. Unable to enter the society of the dead, it must lead a pitiful existence on the fringes of human habitation. In its discomfort, the soul is liable spitefully to inflict illness upon the living. Elaborate observances are required to divert its hostility. The 'great feast' terminates this miserable period by honoring the now dry bones of the deceased, confirming the soul's arrival in the land of ancestors, and marking the reestablishment of normal relations among the survivors.
>
> (1991: 34)

As in Japan, in Borneo, the spirit of the dead is not considered to go to the next world immediately after physical death. It is outside the body, but is still wandering around. This period is thought to be the most dangerous for the living, and the death is confirmed only when the body becomes merely dry bones, and the 'great feast' is carried out to celebrate this. Similarly, in traditional Japan, the homeless spirit (which is distinguished from the ancestral spirit) was supposed to be sent to the next world.

In Japan, there are two words that represent the soul. The souls of the recent dead are called *shiryō* (ghosts), and the souls of the ancestors are called *sorei* (ancestral spirit) (Takeda 1998: 85–86). The former are objects to be feared, as they are still not free from the grudge they held when they were alive. They may also become *onryō* (a vengeful spirit), bringing a curse on people living in the world. On the other hand, *sorei* are respected by Japanese people, and are thought to look after the descendants and wish for their prosperity. The status of the soul changes with time, which is seen in the examples of secondary burials in chapter 2. The souls of the recent dead are considered to be wandering between this world and the next, and they are also considered to be dangerous to the living unless properly treated. The souls of the recent dead are transitional-beings, which are particularly frightening and polluting until the proper ritual is conducted to send them to the next world so that they become *sorei.* For this, not only the rituals of breaking bonds, but also rituals to help the deceased's spirit achieve Buddhahood, together with memorial services were performed until the deceased's spirit was fully transformed into an ancestral spirit guarding the household.

1.1.2. Wake

When death of an individual was confirmed, a wake was conducted before the funeral. In principle, a wake was open to everyone; however, those who came to a wake were generally only the deceased's family, relatives and neighbours from the same village (Murakami 1990: 39). They gathered in the house of the deceased, and a priest came to chant a sutra after sunset. The deceased's family sat up all night with the body, and 'they took turns making sure the incense and candles continued to burn so that no evil spirits would enter the deceased's body' (Saitō, 50-54: 1986, cited in Suzuki 2000: 44).

1.1.3. Funeral procession

On the day of the funeral, members of the immediate family wore white robes (*shiro-moku*), white Japanese-style socks (*shiro-tabi*), and clogs with white thongs (*shiro-hanao*). This distinguished kin with the closest relationships to the deceased from those with more distant relationship, who wore black, indicating the degree of contamination from death pollution. A dinner known as 'departure food' (*detachi no zen*) was served around noon, which was the last dinner for the family and relatives with the deceased. A cup of rice wine was served to all family members in order to purify them from death pollution. In the meantime, guests started to arrive at the house, and the funeral finally began in the late afternoon with the arrival of the priest, who officiated and recited a sutra. After this, each person lit an incense stick. The body was displayed for the last time so that the family members could view the deceased and put food, thread and needles (for women), a razor (for men), coins (*rokumonsen*), and other personal belongings in the coffin. These items were for the

deceased to use both on their journey and while in the afterlife (Suzuki 2000: 46). The coffin was then finally nailed shut by the family, using a stone as a hammer[7]. As soon as the coffin was out of the house, the living room was swept clean (Shintani 1992: 28), and a rice bowl which the deceased used to use was smashed on the ground in order to keep the deceased's spirit from returning home (Suzuki 2000: 46). These are also other bond-breaking practices.

Next the procession took place. All the men from the *kumi*[8], apart from the very old and the very young, walked in the procession to the burial site near a temple. A mortuary tablet was held by an heir. Flags with the deceased's name were also held by people in the procession, which helped to show other villagers who had died (Yamada 1996: 47). Those who carried things (such as lanterns, incense burners, and a mortuary tablet) were adult men, while women and children usually went by rickshaw (Murakami 1990: 41).

1.1.4. Funeral

On arrival at the temple, items such as a mortuary tablet, tables, flowers, and incense burners, which were brought over by people in the procession, were decorated. Incense was burned and offered by each member of the family and then by the guests. After the funeral, small wooden boxes of sweets called *mitsugumi* were distributed to each participant (Murakami 1990: 42).

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[7] Nails were considered effective to keep the deceased separate from the living (Suzuki 2000: 46).
[8] The community cooperative or mutual-aid group which consisted of five to seven households (Suzuki 2000: 42).

1.1.5. Burial

After the funeral, the coffin was carried to the burial site, and was placed into the grave. The chief mourner first shovelled soil on top of the coffin, then other family members and relatives followed in turn. Each time a person finished shovelling, he or she laid the shovel (*kuwa*) on the ground instead of handing it to the next person. During this ritual, the priest chanted a Buddhist sutra. Suzuki (2000: 46) also defines this as part of the bond-breaking ritual. Other such rituals were to follow: 'The bereaved family took off their clogs and left them at the site. Those members responsible for filling in the grave remained, while the rest of the procession returned home without turning back. Upon reaching home, they sprinkled salt over their clothes and rubbed and washed their hands with it to cleanse themselves from death pollution before entering' (Suzuki 2000: 47). This performance of cleansing is called *kiyome*.

1.1.6. Memorial services

On the 7th day and the 49th day after a death, the family invited priests and their relatives for memorial services. The 49th day after a death was called *shijūkunichi*: it is now that the mourning period is completed since it was considered that the spirit of the dead had arrived in the world of the dead. The memorial services were comprised of priests' sutra recitation and worship by the deceased's family. 'The rites of achieving Buddhahood were performed from the time of the funeral procession to the 77th memorial service (*nanajū nanaki*) in the form of prayers at the household altar, whereas the rites of memorial services were conducted during the Festival of the Dead (*bon*), at the New Year (*Shōgatsu*), as part of the equinox (*higan*)

celebrations, on the monthly anniversary (*gakki*) of death, as a periodic anniversary rite (*nenki*), and at the final memorial service (*tomurai-age*)[9] by inviting a priest for a sutra recitation' (Akata 1986: 89, cited in Suzuki 2000: 48). Once the spirit reached the world of the dead, it was not considered as dreadful as before; however, it was important for the family to keep taking care of the deceased's spirit. It was considered that otherwise the spirit could bring the living bad luck.

1.1.7. Summary of traditional death rituals in Japan

In this manner, death rituals were traditionally carried out in order to peacefully send the deceased to the world of the dead. Within the framework of the rites of passage there are three steps, the rite of separation (wake), transition (funeral and burial), and incorporation (memorial services); however, in Japanese traditional death rites the rite of attempted resuscitation or confirmation of death comes before the rites of separation. Whether to consider these rites one or the other is still debatable. Suzuki (2000:48) regards activities taken immediately after death, such as *tamayobai* (calling the soul), as rites of attempted resurrection, or rites of attempted incorporation. However, I choose to interpret them as rites of confirmation of death. Indeed, rites such as *tamayobai* take the form of attempting the resurrection of the deceased; yet, the living actually perform these rites in order to differentiate a period of time from the ordinary course of events. It seems that the aim of this rite was more likely to confirm the person's death than to restore the deceased to life. (See also Namihira (1990) in section 1.1.1.)

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[9] This service was conducted on the 33rd or 50th anniversary of death, when the deceased was considered to have finally been transformed into a household ancestor and a Buddha (Suzuki 2000: 48). It means that the spirit of the deceased finished all the rites of passages and was finally ready to join the world of the gods (Inokuchi 1977: 168).

The rites of separation follow after confirming death. Many rituals were conducted to break the bond between the deceased and the living. Once the soul departed from the body, it was not supposed to re-enter the body. The soul was, however, not considered to have gone to the world of the dead until the rites of the memorial services, which are analogous to the rites of incorporation, were carried out. Between the rites of separation and those of incorporation, funeral rites were conducted as rites of transition. During this period, the deceased's spirit was regarded as an object of dread, and the living devoted themselves to sending the spirit to the next world as carefully and peacefully as possible. Death was considered polluting. *Kiyome* (cleaning) was performed in order to remove the pollution of death from the people who took part in the ritual, the utensils used for it, and the space in which the ritual took place. The concept of inversion also significantly supported the idea that the deceased's spirit was regarded as the object of dread and polluting. It was not desirable for the living if the deceased's spirit returned to the body or lingered around in this world. The rituals of inversion were carried out in order to keep the deceased's spirits away from the living.

1.2. Funeral rituals in contemporary Japan

As in other societies, modernization has changed people's way of living and the function of society in Japan. As Nudeshima (1991) argues, the breakdown of the extended family and the loosened community bond resulting from modernization (i.e., greater educational opportunities, the division of labour, professionalization, migration to the cities, and salaried income) resulted in significant changes in Japanese death rituals as well.

Suzuki (2000) argues that the process of commercializing the funeral ceremony paralleled the estrangement of death and dying from communities. 'Unlike the past, when a community functioned as a cooperative mutual-aid organization, contemporary neighbours rarely assist the bereaved' (Suzuki 2000: 215). According to Suzuki (2000), this is because of the increased occurrence of hospital deaths and the gradual decrease of community elders who know traditions and customs, resulting in the loss of the knowledge of how to prepare the corpse for funerals. Funeral professionals started to provide services that handled the physical remains of the deceased, and people began to gain knowledge of how to handle the corpse solely through the industry. This discouraged ordinary people from conducting funerals themselves. 'Consequently, funeral companies with specialized knowledge have come to dominate the field and have widened the knowledge gap between professionals and consumers' (Suzuki 2000: 217).

Traditional funeral rituals, however have been preserved, are still observed in contemporary Japanese funerals, which are made up of three distinct parts: (1) the wake; (2) the funeral ceremony; (3) the cremation; and (4) memorial service. Suzuki, who conducted her fieldwork with a commercial funeral company in Japan, and actually attended some of the funerals, describes the contemporary Japanese funeral ceremony in quite some detail.

1.2.1. Wake

Since few people nowadays have houses big enough, the wake and the funeral ceremony are rarely conducted at home. The bereaved family usually rents out a funeral auditorium.

The wake takes place on the evening after death. Friends, neighbours and other associates usually come to express their condolences. The wake commences with a Buddhist priest chanting sutra. The sutra chanting usually lasts for about twenty minutes, and is followed by the incense offering (*shōkō*). The offering begins with the closest family members and continues until all of the guests have offered incense at the altar. In the meantime, the priest continues to chant. When all have finished offering the incense, the priest presents some Buddhist sermons (*hōwa*), and then the ceremony for the wake is completed.

The priest and all the guests then leave the place, but the family and relatives remain for the vigil. They are supplied with vegetarian food and alcohol served by the funeral assistants. 'At community funerals, wakes commonly served only vegetarian food (*shōjin*), no meat or alcohol'; however, 'drinking is not taboo at contemporary wakes or at funerals. On the contrary, it is an appropriate or even necessary gesture to demonstrate one's sympathy, pain, and sorrow over a particular death' (Suzuki 2000: 88).

As mentioned above, in the old days the deceased's family kept awake all night with the body in order to keep the incense and candles burning on the altar so that no evil spirits would enter the deceased's body. However, according to Suzuki, in contemporary times, quite a few families do not have anyone stay with the deceased for the vigil:

> [...] funeral staff and funeral conductors are often asked the same questions by family members: Is it really necessary to stay with the deceased at night? Will anyone be at the auditorium for the night shift? Funeral professionals commonly state that it is not compulsory to stay with the deceased during the vigil and that there are three funeral professionals on the overnight shift. Upon hearing this, most families conclude that they do not need to remain because, as they put it, "The deceased is taken care of by the funeral staff." The funeral staff make sure the family understands that they will not be in the deceased's room itself but in the night-shift room downstairs. A typical response is: "It's okay [*sorede kekkōdesu*], as long as someone is in the building." The bereaved, however, should not be solely blamed for this change in practice; even the funeral professionals themselves put out all incense and candles at night to avoid the risk of fire.
>
> (Suzuki 2000: 89)

Suzuki points out that the reason why the deceased's family do not take care of the body as much as before is firstly due to the absence of the perception of impurity, death pollution, and evil spirits during the period between the announcement of death and prior to the funeral ceremony, and secondly because the family members still view the deceased as if he or she was still alive. The family she observed had left some relatives with the deceased not because they considered that the deceased was in the dangerous transitional state, but because they thought 'she will be lonely'. The funeral staff were showing the similar view towards the dead; they complained about the deceased's family who did not want to undergo the vigil, saying, "They are not fully showing respect to the deceased." Suzuki concludes that the belief exists in the 'living-dead'. The body of the deceased is treated with extreme respect and caution not because the dead body is considered polluted or it has the possibility of being haunted, but because it is viewed as alive. According to Suzuki's fieldwork

observations, this belief controls the family's behaviour until the end of the funeral ceremony, i.e., just before the cremation.

1.2.2. Funeral ceremony (*kokubetsu shiki*)

The core event of a funeral ceremony is called *kokubetsu shiki* (the farewell service), and is conducted on the day after the wake. Male mourners put on black suits with black neckties. Female mourners wear black mourning *kimonos* or black suits. When the ceremony starts in the afternoon, the funeral assistants usually serve vegetarian lunch boxes to the family and relatives. The same type of lunch box is also placed in front of the coffin.

A Buddhist priest enters the hall and seats himself at the centre of the front stage, where the altar is placed, and then the funeral ceremony commences. The Buddhist priest officiates, and recites a sutra. 'All the various associates of the deceased attend, and burning incense is passed round so that each can add a pinch to the fire as a token of farewell' (Hendry 1995: 144). Then telegrams (*chōden*) are read from those who were unable to attend. After the telegrams have been read, the memorial address (*chōji*) is offered by participants who knew the deceased well, followed by the closest next of kin, who come to the front of the hall and bow to thank everyone for having come.

Then the body is displayed for the last time at the *nobe no okuri* (Putting Out to Pasture) ceremony (Aldwinckle 1997: 3). This is also called *shukkan* (the departure of the coffin) and is the most emotional moment. This is the last time for the bereaved to see the deceased, and the time to say farewell to him or her. Usually the bereaved family put flowers, food and some objects which the deceased used to use in the coffin. Then the coffin is finally nailed shut.

1.2.3. Cremation

The coffin is carried into a hearse to make the journey to the crematorium. Those who go to the cremation are normally close relatives and friends of the deceased. At arrival, the body will be moved from the hearse and taken to the front of the incinerator. The bereaved are often asked to offer the final incense to the deceased. The Buddhist priest recites a sutra for the last time. The coffin will then be pushed through the chamber door. When it goes out of site, a cremator says to the bereaved, "It is time to ignite" and asks the mourners to press the button to start the ignition. According to Suzuki (2000: 91), many mourners hesitate to press this button because they perceive their action to be the final death sentence for the deceased. If none of the bereaved wants to press the button, one of the cremators will press it:

> But one time when a cremator did so, an outraged chief mourner yelled at him, "You are killing my mother!" [*Haha wo korosu kika*]. "I had to apologize to the son for killing his mother," the cremator explained with a suppressed smile and added, "That was unpleasant" [*Are niwa ōjō shimashitayo*].
>
> (Suzuki 2000: 91-91)

Such an example shows that the dead are treated as 'the living dead' (Suzuki 2000), and they are not necessarily considered finally dead until cremation is conducted.

It usually takes one or two hours to cremate the body. When finished, the bones are placed in the urn. Immediate family members take up chopsticks (usually made of bamboo), and pass bones to the chopsticks held by the next closest family member, who will place them in the urn. After the immediate family, everyone present takes a turn putting bones, from the lower body and then the upper, into the

urn, so that the body is not placed upside-down inside its final resting place (Aldwinckle 1997: 4). The Adam's Apple is said to resemble a Buddha sitting cross-legged[10], therefore a piece of this bone is picked up by the chief mourner, and placed on top of other parts together with the skull.

1.2.4. Memorial services

As mentioned earlier, traditionally the mourning period lasted for at least forty-nine days, and on every seventh day of this period the deceased was worshipped by family members, relatives and priests. However, Suzuki reports that more than two-thirds of the customers of the funeral company that she worked for during her fieldwork conducted the deceased's seventh-day memorial services (*shonanoka*) immediately after they had returned from the crematorium. Furthermore, seventh-day memorial services are now practiced more and more often on the same day as the funeral because it is difficult to gather relatives on the forty-ninth day (*shijūkunichi*). 'The seventh-day memorial is the final family gathering for the deceased until the first-year memorial service (*isshūki*), held one year from the day of the deceased's death' (Suzuki 2000: 118).

For this ceremony, the priest reads the sutra again, and when finished, all the mourners offer incense to the deceased, 'who has been safely incorporated into the world of the dead' (Suzuki 2000: 119). The meat-based dishes are served after this,

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[10] The bone called the Adam's Apple (*nodo-botoke*, which literally means 'throat Buddha') here is not really a bone from the throat but from the spinal cord. (i.e., the bone that connects the neck and the skull (Suzuki 2000: 233).

which indicates the end of the mourning period. In this manner, the entire funeral process is significantly shortened in modern Japanese society[11].

1.2.5. Summary of contemporary funerals in Japan

The contemporary Japanese funerals emphasize rituals to reminisce about the dead and to say farewell to the dead rather than those to send the soul of the dead to the next world which were conducted in traditional funerals. The perception of impurity, death pollution, and evil spirit is absent; instead, the dead are treated as if they were still alive. The whole process is shorter in length, omitting the long mourning period seen in traditional funerals.

1.3. Differences between funeral rituals in traditional and contemporary Japan

In this section I explicitly point out some of the main differences between traditional community rituals and commercial ceremonies: (1) the length of the rituals; (2) the concept of 'the living dead'; (3) more personal funerals; (4) the relationship between the living and the dead; and (5) disappearance of a funeral procession.

1.3.1. The length of the rituals

The most distinctive difference between the two is the length of the whole process. Traditionally in Japan, once an individual had died, the rites of confirmation

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[11]In the case of the funeral ceremony which Suzuki observed the whole process was entirely completed within fifty

of death (*tamayobai*) were carried out before the rites of separation. The funeral ritual was full of rites of separation and transition. After the long transitional period (the forty-ninth day after a death), the spirit of the deceased was considered to have reached the world of the dead (incorporation), and the mourning period was completed at last. On the other hand, the contemporary Japanese death ritual is highly compressed, and the whole process normally takes only 2–3 days. In many cases, even the rite of incorporation (i.e., memorial service) is carried out on the day of the funeral, after the cremation.

1.3.2. The concept of 'the living dead'

In contemporary Japanese death ritual, the dead tend to be regarded as alive until the moment of cremation. This leads to a diminution of death related pollution and the fear of evil spirits. This is an interesting contrast, as in the past it was believed that if the spirit was treated as if it were alive, it would not go to the next world successfully, and it would become *onryō* and possibly possess the living.

Suzuki argues that the concept of living-dead is attributed to the linguistic differences between a 'corpse' (*shitai*) and a 'deceased's remains' (*itai*):

> The latter term implies a body of one's family, relatives, or a close friend and when used by others, demonstrates respect to the deceased and his/her family. The former in contrast, applies to any cadaver which has no relations to the ego and its use denotes the vision that a corpse is a thing or an object. Thus, 'deceased's remains' demands itself to be treated in a way he/she has been treated when alive.
>
> (Suzuki 1997: 73)

Namihira also explains that:

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hours after the individual's death.

> '*Shitai*' generally means the body of the dead. On the contrary, '*itai*' or '*igai*' mean 'the remained body' for the family and people concerned. This word also implies that the deceased's relationship with others while he/she was alive still remains through the body even after his/her death. The reason why a doctor calls the patient's dead body '*goitai*'[12] is explained by this concept.
>
> (Namihira 1990: 49)

The fact that people choose the word '*itai*' rather than '*shitai*' according to the different context implies that there is a clear distinction between the concepts of the living-dead and a corpse in contemporary Japan. It is also important to understand the concept of the living-dead when we consider the fact that *itai* is normally taken back home before the funeral, which does not usually take place at home.

1.3.3. More personal funerals

Suzuki also indicates that modern funerals increase the personal elements in order to make up for their limited allocation of time. In other words, they emphasize a positive remembrance of the dead. 'Funerals have become an occasion for family, friends, and colleagues to share and crystallize their memories of the deceased. The most crucial part of constructing a positive memory is the memorial address (*chōji*)' (Suzuki 2000: 213). The memorial address emphasizes 'the beautification of the deceased's life: honouring their contributions; appreciating their kindness, their generosity, and their social achievements; and learning from their good deeds' (Suzuki 2000: 214). In so doing, the funeral ceremony transferred into a positive experience which is regarded significant for the living. 'The faults of the deceased in his or her lifetime may be amended, resolved, and forgiven by the participants at a

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[12] *Goitai* is a more respectful form for the word *itai*. (footnote added by author)

good funeral. As one funeral professional said, "A good funeral is said to be the one that erases the deceased's bad deeds" (*yoi sōgi wa kojin no kakono ayamachiwo keshisaru*)' (ibid.).

1.3.4. The relationship between the living and the dead

Suzuki points out that the difference between traditional community rituals and commercial ceremonies lies not only in content, but also in how the values expressed in both occasions are exchanged between the living and the dead. In community rituals, the relationship between the living and the dead is symmetrical. For example, belief in dangerous spirits maintained the balance between the parties until the 49th day after death, when the deceased was considered to have been transformed into a harmless, peaceful spirit. Corpse and death were regarded as polluted, and the deceased's spirit was the object of dread. Therefore, the living had to treat the dead very carefully, with awe and reverence. In contemporary funeral ceremonies, however, the living have more power than the dead. It is the living that decide how much honour should be given to the deceased (i.e., during the memorial address), and who evaluate the deceased's life at a funeral.

1.3.5. Disappearance of a funeral procession

It is also important to point out that contemporary death rituals no longer make use of a funeral procession; a hearse is used instead. As mentioned above, during the Taishō period, funeral processions started declining due to the development of public transportation. This led to the appearance of a hearse at death rituals. Inoue (1984) points out another reason for the disappearance of the funeral procession, namely, the

fact that such processions lost their sacredness. It is supposed that one of the main functions of funeral processions was to display one's death to the outside world. The fact that there were flags with the deceased's name in the procession, or an heir holding a mortuary tablet, supports this idea. Funeral processions, however, had greater purpose than just indicating a death to the wider society. According to Yamada (1996), a different palanquin and coffin were used in the procession depending on the social class of the deceased. Some funeral processions were enormously developed, loud and showy, in order to show off the deceased's high social class, and these became a target of criticism in society. A letter from a reader to the *Yomiuri Shinbun* (The Yomiuri) on 21st April 1914 criticized a funeral procession at that time as follows:

> More people have stopped having a funeral procession these days. It is a good tendency. It does not seem to be a preferable custom to parade in a busy town with lots of flags and flowers; in general, it seems that they put the dead on show. It is so disgraceful to see people in a procession smoking and talking away as if they were on a pleasure trip. If funeral processions are abolished, this will disappear. The good tendency should become more prevailing.
>
> (Inoue 1984: 130)

In this manner, funeral processions that became too showy and disgraceful were the object of criticism. Together with other external factors caused by the development of public transportation, in the middle of the Taishō period funeral processions started to be replaced by a hearse[13]. This social phenomenon moved the core event of the funeral from a funeral procession to a farewell service (*kokubetsu*

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[13] Hearses were originally designed for the lower class people who could not afford a funeral procession so that their funerals could be more simplified. Hearses also functioned to mask differences between various social statuses (Yamada 1996: 49).

shiki). In other words, the core event was transformed from the rite of 'sending out' to the rite of 'accepting a condolatory call' (Murakami 1997: 106)[14]. At the same time, death became indicated socially more as a farewell service. According to Yamada (1996: 46), who explains how a farewell service has become the occasion to express death socially to others, the size and luxuriance of the altar at a farewell service has become associated with the social status of the dead and the bereaved. Yamada (1996; 2004) also points out that the disappearance of a funeral procession and the spread of using a hearse made it difficult to compose death as a departure to another world. Yamada (1996) continues that:

> Within a death ritual conducted up until Taishō period, death was transformed to a motif as 'departure' by a palanquin in a funeral procession, and was accepted by the living. A funeral procession was a transportation ritual with time and space, where the dead got on a palanquin and moved [from home to the burial site] with a mortuary tablet, offerings, lamps, and so on. It was exactly a 'transition'. [...] The abolition of a funeral procession resulted in using no palanquin, and it made it difficult to transform death to 'departure'. [...] At *kokubetsu shiki* [a farewell ceremony], a coffin, a mortuary tablet, offerings, and lamps were placed all together in front of a sacred altar. There, death was transformed to 'a revival in another world' which omits both time and space, as a result of the omission of a 'journey' as a 'transition'. In other words, the emphasis was shifted from 'transition' as in a funeral procession to 'incorporation' of death as in revival of the dead in the other world.
>
> (Yamada 1996: 52)

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[14] A farewell service, *kokubetsu shiki,* is a ritual to call others in. The reason why this became prevalent is thought to be associated with the development of information technology, such as telephones (Yamada 1996: 55).

The increasing prevalence of the farewell ceremony (*kokubetsu shiki*) and the decline of the funeral procession resulted not only in saving time, space and expense, but also shifting the main role of death rituals from 'transition' to 'incorporation'.

1.3.6. Funeral rituals in traditional and contemporary Japan

Table 1 summarizes the differences between funerals in traditional and contemporary Japan. Compared to traditional ones, funerals in contemporary Japan are shortened in length and have less ritualistic meanings. They place more emphasis on bidding farewell to the dead and showing a positive remembrance of the dead to the bereaved than practicing rituals to avoid death pollution, impurity, and evil spirits. In contemporary Japanese funerals, the soul of the dead seems to be thought to reach the next world immediately after death. This is perhaps due to a practical reason; there is not enough time for contemporary Japanese people to conduct long complicated series of rituals. It can also be said that this is because the dead is no longer considered as an object of fear but as a living dead. All the complicated procedures related to a fear towards the dead and death pollution can be omitted if there is no such a notion. *Chōji* (the memorial address) also plays an important role in the disappearance of the traditional rituals. *Chōji* emphasizes the beautification of the deceased's life: appreciating their social achievements, kindness, and generosity. Here the dead sound like they have no regret in this life, and are ready to go to the next world without a grudge. It seems that in contemporary Japan, the dead's soul is supposed to be already peaceful enough to settle in the next world at the time of a funeral. In other words, the dead is thought to be reborn in the next world at the time of funeral. Contemporary Japanese funerals, therefore, lack concepts of 'separation' and 'transition', and their role is condensed in the celebration of 'incorporation'.

	Traditional funerals	Modern funerals
Rites of confirmation of death (the occurrence of death)	- *Tamayobai* (calling the soul)	
Rites of separation (the wake)	- Rituals to protect the dead body from malevolent spirit; - Inversion rituals to differentiate the dead from the living; - Bond breaking rituals between the living and the dead.	- The absence of the perception of impurity, death pollution, and evil spirit; - The concept of the 'living dead'
Rites of transition (the funeral ceremony and burial/cremation)	- Funeral procession which is a ritual to send the deceased out to the next world by emphasizing the dead's 'journey' from this to the next world; - Death is considered dirty; - Relationship between the dead and the living is symmetrical.	- *Kokubetsu shiki* (farewell ceremony) which emphasizes a revival of the dead in another world; - *Chōji* (the memorial address) which emphasizes a positive remembrance of the dead; - The omission of a 'journey' as a 'transition'; - The dead are treated as if they were still alive until cremation is conducted; - The living have more power than the dead.
Rites of incorporation (the memorial services)	- Memorial services (The spirit of the dead is considered to have arrived in the world of the dead on 49th day after a death.); - Final memorial services (The deceased was considered to have finally been transformed into a household ancestor and a Buddha on the 33rd or 59th anniversary of death. This is the time when the spirit of the deceased finished the rites of passages).	- Memorial services are conducted on the day of the funeral (The deceased are considered to have been incorporated into the world of the dead on the day of the funeral.); - Short mourning period.

Table 1. Differences between funeral rituals in traditional and contemporary Japan

2. Summary – a new model for death

In this chapter, we have seen that contemporary Japanese funerals lack concepts of 'separation' and 'transition', and their role is condensed in the celebration of 'incorporation' and 'a revival of the dead in the next world'. For the bereaved, it is easier to celebrate 'incorporation' of the dead into the next world at the time of funeral if the dead are considered to have died a good death. If a bad death occurred, it is difficult for the bereaved to believe that the dead will reach the next world smoothly. It can be said that the period of dying has significant meaning for funerals—the rite of incorporation.

Dying a good death is an explicit aim of the modern hospice movement, and the hospice programme is conducted for patients to achieve this aim. For the reason above, dying a good death is important not only for the dying but also for the living in contemporary Japan. Can it be said that for PCU patients and their family, for example, the journey to the next world starts on admission to a PCU, where the patients are helped to die a good death?

My conclusion is that the dying process can be interpreted as the transitional period, which modern funerals lack—a notion of 'journey'. When discussing the rite of passage concerning death in Japan, the dying process and funeral practices can be combined as seen in Figure 2.

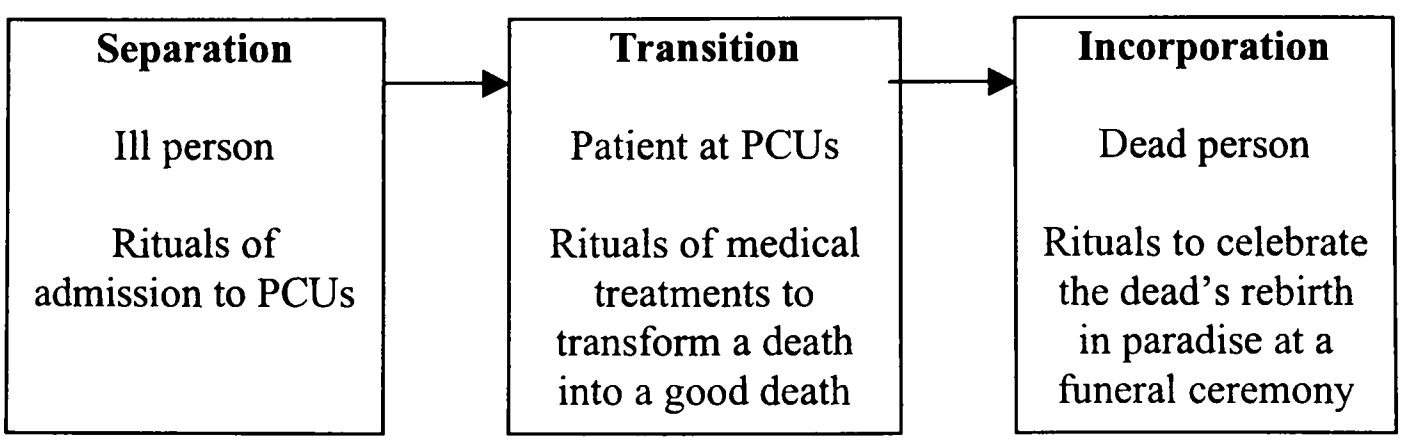

Figure 2. Rites of passage (the dying process)

This new way of viewing the roles of funeral rituals and dying process provides a means to explain aspects of the modern funerals which function without a notion of 'journey' and lack a concept of death pollution. In this new model, the dying process plays a role of journey and during this period, all negative concepts associated with death are supposed to be removed so that the dead can arrive in the next world smoothly at the rite of incorporation (at funerals).

In the following chapter the Japanese concept of good death and view of health and illness will be introduced in order not only to understand how patients perceive their illness and death but also to better understand how they spend their dying process. Chapter 5 and 6 will then look at the dying process of the PCU patients, based on what I witnessed during my fieldwork. Assuming that the dying process plays a role of a transitional period before funerals where rites of incorporation are conducted, I would like to investigate how the transitional journey to the next world proceeds within Japanese hospices and palliative care units.

Chapter 4: The Japanese View of Health, Illness, and Death

My fieldwork on dying patients receiving palliative care in contemporary Japan clarifies that the traditional Japanese holistic concept of health and illness coexists with Western medicine, and is still highly evaluated within the realm of palliative care. This phenomenon can be well explained by the concepts of *tairyoku* (physical power) and *taichō* (physical condition), terms which I often heard during my fieldwork. Interestingly, these concepts also affect patients' (and their families') decision-making processes when they receive medical treatments. In this chapter, I will explore the concepts of *tairyoku* and *taichō* as well as the concept of good death in Japan.

1. Illness - a part of healthy life

The Japanese concept of health and illness is holistic. It considers 'all the parts of the body to be interconnected and mutually affecting each other, and affected by the environment, both social and physical' (Lock 1980: 217). This also assumes that there is no perfect health as such, as health is not a static state. When everything is relatively in balance, a person is considered to be in a state of good health.

According to Ohnuki-Tierney (1984: 51), many Japanese regard themselves as somewhat less than healthy, if not sickly. 'The concept of *jibyō* clearly reflects this aspect of Japanese attitudes toward health and illness. [...] *Jibyō* means an illness that a

person carries throughout life, and suffers at some times more acutely than at others' (Ohnuki-Tierney, 1984: 53). Examples of *jibyō* include shoulder stiffness, constipation, low blood pressure, headaches and dizziness. Common to all these *jibyō* is the fact that they are chronic and incurable.

Another concept, *taishitsu,* is closely linked with the notion of *jibyō. Taishitsu* is 'the nature of the constitution with which one is born' (Ohnuki-Tierney 1984: 54). The common *taishitsu* are, for example, healthy, ordinary, weak and unenergetic, hypersensitive, and so on. In a sense, as Ohnuki-Tierney suggests (ibid.: 72), in Japan:

> Individuals learn to live with weakness of the body, just as they live their daily lives with the knowledge of ever-present danger and evil. [...] In this context, it should be pointed out that in the Japanese Morita therapy, the indigenous so-called psychotherapy developed for the treatment of neuroses, the basic premise is that human beings are weak. Therefore, the first step for recovery according to this method is to learn to acknowledge one's weaknesses and live with them.
>
> (Miura and Usa 1974; Reynolds 1976, cited in Ohnuki-Tierney 1984:72)

Inherent characteristics are given. Individuals should adjust to these, rather than attempt to manipulate them. Therefore, Japanese people who have a weak *taishitsu,* or some kind of *jibyō,* usually consider themselves normal, and try to live harmoniously with what they are given, instead of trying to change it.

This holistic view is also seen among patients with other kinds of illness. Cancer is also sometimes seen as *jibyō,* especially when patients recognize that the disease is no longer responsive to curative treatment, and before the body has deteriorated badly. I heard many cancer patients new to the PCU say to their doctors that they had to live with cancer until they die, or that they wanted 'to get along' with cancer. Instead of

manipulating the cancer itself, they mostly try to adjust themselves to their diseased body. They try to build up more body energy, which has been decreased due to cancer, and try to generate a more harmonious condition with their cancer. The concepts of *tairyoku* and *taichō* are commonly employed by PCU patients and their families in an attempt to enhance the patients' condition holistically. In the next section, we will examine these two concepts in further detail.

1.1. The concepts of *tairyoku* and *taichō*

During my fieldwork at PCUs and other hospices, words such as *tairyoku* (体力)[1] and *taichō* (体調)[2] were often heard. These words are commonly used in everyday conversation[3]. However, in an environment where topics related to health and illness are more common, such as a PCU, these words are heard even more frequently than in other situations. The concepts of *tairyoku* and *taichō* also demonstrate the Japanese holistic view of health. These concepts are generally used as a measurement of the total health condition, and *tairyoku* is thought to have a curative power. During my fieldwork in Japan, these words seemed to be the key terms in which patients described how they were.

Tairyoku literally means one's physical power, but it also means the vital bodily energy flow which is conceptually similar to the Japanese *ki*[4] or Chinese *qi*[5]. For instance, the following are typical statements made by patients at hospices:

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[1] 体 (*tai* or *karada*) and 力 (*ryoku* or *chikara*) mean 'body' and 'power' respectively.
[2] 体 (*tai* or *karada*) and 調 (*chō*) mean 'body' and 'condition' respectively.
[3] These words are used especially when people greet each other.
[4] According to Doi (1973: 96), the concept of *ki* is used particularly in expressions to do with emotion, temperament and behaviour. It also indicates the movement of the mind from moment to moment (Doi, 1973: 109). Lock (1980: 85) noted that *ki* is considered dynamic, and is also closely related to the state of health. For example, *genki* ('good health') literally means 'original *ki*' but also implies a steady flow of *ki*. The concept of *ki* explains that 'health and ill health are both normal', and 'the body continually moves in and out of both states' (ibid.).

Without *tairyoku,* human beings cannot survive.

(My husband said) his *tairyoku* has decreased since last summer (and since then his cancer seems to have spread).

I'm not very confident about leaving the PCU, as I have no *tairyoku* at the moment.

An examination of patients' narratives suggests that *tairyoku* is constructed from four closely related components, these being gentle but not extreme exercise, nutrition, rest, and state of mind. The following are quotations which demonstrate the importance of the above four components to increase *tairyoku*:

Mrs. M exercises everyday. She also takes many kinds of food in order to regain *tairyoku* and increase her immunity.

(nurse)

What he (a patient) calls treatments are yoga and health food. He also wants to eat to build up his *tairyoku.*

(doctor)

If I become able to eat, I think I will have more *tairyoku.*

(patient)

Patient: (Even when I lost my ability to taste due to radiotherapy), I ate and ate by some means or other, although I was asked by other patients how I could manage to do that despite the fact that I could not taste anything.

Patient's wife: I also told him to eat and eat, as nobody can live without *tairyoku.*

(at a PCU outpatient consultation)

My mother seems to strongly believe that rehabilitation will increase her *tairyoku* and she will recover sooner or later.

---

[5] *Qi* is 'the breath and substance of life, the vital force that maintained the health of an individual, the well-being of

(patient's daughter)

[...] I wonder if I would live longer [i.e. have more *tairyoku*] if I stay somewhere warmer and rest in order to recuperate [...]

(patient)

Patient: When I first entered here, I really felt ill, and it was so hard for me to eat. I also had a hard time mentally, but I've felt much better since the last few days, thanks to you. I've become able to eat, you know, I have more power [i.e., *tairyoku*].

Doctor: The power to hang on.

Patient: Eating makes a big difference, doesn't it?

(on a doctor's round)

I won't be able to walk anymore if I don't eat.

(patient)

> My face is swollen so much and I'm depressed ... I feel I'm losing my *tairyoku* now...
>
> (patient)

In this manner, it is believed that *tairyoku* is built up on the basis of exercise, nutrition, rest, and a calm state of mind. If one of these is lacking, the whole balance is thought to be disturbed, and this leads to a decrease in *tairyoku.* For instance, if one does not eat properly, one will lose one's mobility, become unable to enjoy proper rest and, therefore, to keep oneself in a good state of mind. If, however, all four factors are well balanced, the body is filled with *tairyoku,* which brings good health to a person. Therefore, this balance dominates a person's general well-being, and when a person becomes ill, restoring the balance between the four factors is considered important.

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the family and the prosperity of the dynasty' (Bray 1999: 191).

Taichō, on the other hand, refers to one's bodily condition, and so can also mean the balance of the four factors (i.e. eating, resting, exercise, and state of mind) needed to maintain *tairyoku*. It is therefore thought to be essential to have good *taichō* in the first place, as a precondition of good health. During my fieldwork, I heard many patients say to medical professionals,

I came here to get my *taichō* into good shape.

Normally, patients had already tried many possible cancer treatments prior to entering a PCU. Due to side effects caused by aggressive treatments, patients had suffered from an imbalance between the four factors, which may have caused bad *taichō*. Thus, it is considered important to restore the balance necessary for good *taichō* and so rebuild their *tairyoku.*

Here I would like to discuss *tairyoku* rather than *taichō* as a key concept, because *taichō* refers merely to a static and basic condition, while *tairyoku* is a dynamic and powerful agency built upon *taichō*. Furthermore, people use *tairyoku* as a measurement of the bodily condition, and it is also believed that *tairyoku* owns special curative power, as explained in the next section. For these reasons, it seems that the concept of *tairyoku* plays an important role for many Japanese people when they talk about their health. It will also be interesting to investigate how patients manipulate *tairyoku* in response to any given physical condition, as this may reflect the general Japanese attitude toward health and disease.

1.2. *Tairyoku* – as a measurement of bodily condition

The word *tairyoku* is also often heard during the patients' decision-making consultations regarding medical treatments. The more *tairyoku* they have, the better

and stronger they feel, and patients seem to prefer having treatment when they have more *tairyoku*:

> I was told that I might not be able to have an operation next time, as I won't have enough *tairyoku* then.

> I heard radiotherapy has no effect on cancer, and it only takes *tairyoku* away, which makes the condition worse.

> Blood transfusion brought on a fever last time. I wonder what will happen to me this time, as I have much less *tairyoku* now than before.

> I'd like to have more *tairyoku*, so I don't want to take any medicine.

The above statements by patients show that even treatments recommended by medical professionals are not always considered preferable, if there is a possibility that they will bring about a decrease in *tairyoku,* and that a certain amount of *tairyoku* is thought to be necessary to undergo an operation. When discussing treatments, patients tend to consider the influence on *tairyoku* rather than the mere physical discomfort caused by side effects. In other words, it can be said that Japanese patients tend to consider holistic consequences in the long run, rather than the immediate cause and effect on the body itself.

What will happen if *tairyoku* starts to decrease, and nothing can stop it? Two patients said the following to their doctors:

> My disease is taking my *tairyoku* away.

I sometimes think I'll have more tumours one after another, then my *tairyoku* will decrease until death.

A decrease in *tairyoku* is thought to indicate that one is approaching the end. A disease undermines *tairyoku* until this vital energy runs out at death.

1.3. *Tairyoku* - as a curative power

It is generally believed by most patients that *tairyoku* has the power to heal. The following are all statements by patients who knew their true diagnosis:

If I stay here [at the PCU], I'll get better and have more *tairyoku*, I think.

I'd like to cure my cancer with my *tairyoku*.

I'm relying on my natural healing power. You [a doctor] told me I have nothing wrong internally. I am fighting my cancer. I'm not about to let it beat me.

The function of *tairyoku* is very similar to that of the immune system in Western medicine – the more *tairyoku* patients have, the stronger they are, and the better able they are to fight a disease and destroy it.

Additionally, as seen in the last statement above, patients seem to believe that their cancer is not fatal if they have nothing abnormal internally. Another patient suffering from tongue cancer also said, "I was told that nothing internal is affected", and displayed a positive attitude towards cure. It seems that if cancer does not affect internal organs, and hence patients are still able to eat, they believe that they can build *tairyoku* to fight their cancer. On the other hand, *tairyoku* may be considered something internal, and thus if a cancer is developed on the surface of a body, it is believed that the

tumour will not affect *tairyoku,* which means that patients can build *tairyoku* within their body.

It is thought that death approaches only when *tairyoku* runs out, and it is widely assumed that if patients have enough *tairyoku,* they can 'throw off' their cancer. The activities to increase *tairyoku*, such as having nutrients, exercise, rest and cultivating a good state of mind, are thus of great significance for patients, although some of them may seem medically meaningless.

In the following sections, we will examine the relationship between *tairyoku* and eating, which was observed as one of the most meaningful acts for the PCU patients during my fieldwork.

1.4. *Tairyoku* and eating

At the PCU it was observed that eating is one of the most significant acts for many patients[6]. A prime example was a patient who would not give up eating, saying, "The day I become unable to eat will be the day I die." Another patient cried and lamented, "Today is the worst day of my life", when her doctor told her that she would not be able to eat again. However, during the course of cancer, patients usually suffer from anorexia. Both physical and socio-emotional factors are possible causes; for example, enlarged cancer tumours putting pressure on the gullet, side effects of treatments, symptoms of cancer itself (such as nausea and vomiting, fever, mouth ulcers), and depression (Yodogawa Christian Hospital Hospice 1997; Kato 2000). A *Terminal Care Manual* (1997), compiled by Yodogawa Christian Hospital Hospice, noted that:

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[6] Ohnuki-Tierney (1984) also describes how contemporary Japanese think of food as an essential source of energy. She also writes on the custom where visitors bring cooked food in to a patient in order to cheer him or her up.

> It is important to clarify whose problem anorexia is and what is the nature of that problem. Sometimes a patient's or a family's idea that 'the body will be weakened without food' is too heavy a burden for a patient.
>
> (Yodogawa Christian Hospital Hospice 1997: 74)

One dietician has pointed out that it is important for patients' families and carers to bear in mind the following:

> (1) to respect a patient's will;
> (2) not to be alternatively happy and miserable at a patient's appetite;
> (3) to accept that a patient will have less appetite in the course of a disease;
> (4) to think up various recipes which reduce the burden for carers (it is sometimes essential for them to have a rest and make use of store-bought, prepared foods for patients);
> (5) to keep a patient's mouth hygienically clean;
> (6) to provide the best environment for a patient (for example, providing ventilation, a clean room, maintaining a comfortable room temperature, music, and some flowers on the table).
>
> (Kato 2000: 16)

Kato (ibid.) also claims that eating is important both to maintain life and to improve a patient's quality of life. It is meaningful for patients to enjoy tasty seasonal meals together with their families. Additionally, Kato (ibid.: 17) recommends recipes for patients who have eating difficulties due to their symptoms, whether vomiting, diarrhea, dysphasia, or oral problems. This implies that it is important for patients to consume food orally with their families, despite the difficulties.

This idea is supported by the fact that many hospices and PCUs in Japan organise events offering seasonally themed meals. For instance, at the PCU in Higashi Sapporo Hospital, voluntary workers hold seasonal events, such as a summer festival in August and a moon-viewing party in September, providing foods traditional to these events. Patients can enjoy foods different from those usually provided by the hospital,

and sometimes patients who reject hospital meals can eat these seasonal ones, as a special treat. Additionally, as medical professionals and other people working at the PCU are all invited, these events provide a great opportunity for patients and medical staff to communicate informally with one another. Everyone eats the same food at the same table and talk about personal topics other than the patient's health. Both patients and doctors can be 'themselves,' escaping the role of patient and carer. I heard some patients saying that they completely forgot to take medicines after enjoying a meal of cooked salmon and vegetables from the communal pot (*nabe*), followed by a session of *karaoke* with other patients and all the people working at the PCU. They had as good a time as they used to have before becoming patients. Additionally, it should be remembered that having meals in company with others can encourage the appetite.

A sixty-three year old breast cancer patient, Ms T, lost her appetite while she was at the PCU. She said to her doctor:

> I can eat if somebody else helps me. I don't feel like eating at all when I'm alone, but a nursing aid feeds me. Then I have more appetite. I become unable to eat when I'm on my own, as I feel pain. People at the nurse station often come to my room.

A nurse at Bihāra in Nagaoka Nishi Hospital said about a seventy-seven year old lung cancer patient that:

> She seems to have no particular pain, but she has lost her appetite. She can't really eat breakfast. But she seems to be able to eat when her son is with her, so she eats lunch and dinner quite easily.

In the former case, having company more or less affects the patient's mental status, which even helps decrease the level of physical pain, and this enables her to eat.

The latter case shows that her son's being with the patient clearly encourages her appetite. A Buddhist monk working voluntarily at Bihāra told me that:

> There was a male patient who used to be at Bihāra ... I often went to his room to have a chat. One day I found that he liked drinking. Then we had even more to talk about. He told me there was a pub which served a very good mixed stew. I had never been there, as it looked a bit dirty. However, I went to the pub at around four, and got some stew for him. We drank and ate together in his room. Then we became even closer.
>
> (T Kiso: personal communication, September 6, 1999)

Having a good meal with others not only helps patients increase their appetite, but also to build good relationships, which may lead to a better mental state. Here is another example which shows that having tasty food is considered important. A chief nurse at Tanaka Surgery in Miyazaki Prefecture said:

> I always ask all patients who come to this hospital what they want to eat, and what they want to do. One old lady told me that she wanted to eat flatfish. So I drove as far as Miyazaki City to buy a very good one for her. Once I had trouble with a requested food ... We sent a patient with leukemia to the Miyazaki Prefectural Hospital in December. When I visited him there with another nurse, he told us he wanted to eat some bamboo shoots. We didn't know what to do, as it was not the season, but someone who knew him well went to the mountains, and dug a few very small bamboo shoots for him. He ate only a little of them. It was his last meal. He died three days after that. Later, I heard that he said it was so delicious.
>
> (M Tanaka: personal communication, October 5, 1999)

Eating is considered one of the biggest pleasures for patients, especially when they have lost other faculties, such as mobility. Therefore, carers usually try to help them eat even if they are at a very terminal stage, and patients themselves also try to eat as much as possible.

Feeding patients also seems to have significant meaning for carers. Ohnuki-Tierney (1984) points out that feeding patients their favourite foods is a non-verbalized method of promoting the mental well-being of patients, and that Japanese people are more likely to feed patients than to vocally express their concerns to them. Ohnuki-Tierney attributes this to a characteristic identified by Caudill (1976); namely, that 'the Japanese are reluctant to verbalize their feelings, although they can do so in writing' (cited in Ohnuki-Tierney 1984: 221)—or, as in this case, in the sharing of food.

1.5. Increasing *tairyoku* with medical assistance

A decrease in *tairyoku* is seen as a threat by both patients and families, since it implies that death is approaching. Although patients who believe in the fighting power of *tairyoku* tend to employ non-medical methods in order to increase their *tairyoku* level (i.e., having nutrients, exercise, rest and cultivating a good state of mind); interestingly, many patients and families start to seek biomedical assistance to increase their *tairyoku* once they realize that its level is decreasing in spite of their best efforts.

Here I give two case studies of patients, Mr Hanazono and Ms Kaji. Both patients were at the terminal stage of their life, and their level of *tairyoku* was considerably decreasing due to the progress of their cancer at the time when the following conversations were recorded.

1.5.1. Case study (1) - Mr Hanazono

Mr Hanazono (aged eighty-five), who suffered from parotid gland cancer, asked for TPN (total parenteral nutrition[7]) in order to put on weight—even though he was still able to take foods orally.

> Doctor: A drip infusion on the back of your hand has the equivalent calories of one rice ball.
> Mr H: If I have it on there it will hurt, so I want to have it on here [points to his chest].
>
> Doctor: Would you like to have one, then?
>
> Mr H: I would like to, as I have never lost this much weight before ...
>
> Doctor: There are normally two reasons for losing weight. Firstly, because one can't eat, and secondly because of the progress of your disease. I think you have lost weight, partly because you can't eat much, so... would you like to try one today?
>
> Mr. H: Well, yes. [...]

Mr. Hanazono was practicing Yoga and taking health food regularly to build up his *tairyoku* and, it was hoped, to eventually cure his cancer. Therefore, it was very shocking for him to suddenly become unable to eat much and to start losing weight. As his doctor explained, one of the reasons for the decrease in *tairyoku* was the progress of the disease. This was also the main reason why Mr Hanazono was not to be able to eat as much as before. Mr Hanazono, however, tried to stop losing weight using TPN, considering that having a full body was the most important thing to rebuild *tairyoku*. In the case of this patient, it is clear that Mr Hanazono did not use the biomedical

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[7] Nutrition maintained entirely by intravenous injection or other nongastrointestinal routes (Stedman's Medical Dictionary 1995).

assistance to cure the disease itself. Biomedicine was used merely as an aid to support his conventional belief in the fighting power of *tairyoku.*

1.5.2. Case study (2) - Mrs Kaji

Mrs Kaji was a fifty-four year old housewife who suffered from lung cancer. When her cancer was diagnosed it was already incurable. She tried many different alternative medicines, such as Chinese medicine and health foods. Her two sons were particularly keen on Chinese herbal medicine prescribed by a Chinese medical doctor in Tokyo.

When I met her at the PCU, she was almost unconscious. Although it was hard for her to swallow, her family was still keen on her using the Chinese herbal medicine (which was in liquid form). They were still asking the doctor to insert a tube from her nose to her throat so that she could take the Chinese medicine without having to swallow. The family was constantly preoccupied with Ms Kaji's nutrition.

Toward the end of the patent's life, the family even asked a doctor to try to manipulate her electrolytes, and to improve her nutritional blood condition by using TPN—even though the doctor explained that giving her treatments at this stage would be a burden for her.

The family also asked the doctor to photocopy the blood test result for them to keep. The following conversation between the patient's husband, son, and doctor suggests that the family were thinking that her cancer had affected her *tairyoku* rather than the organs themselves:

Doctor: [...] Yesterday's blood test result shows electrolytic imbalance. This is abnormal. Electrolytes are always in balance in order to maintain our homeostasis. Even if you take a lot of salt, the sodium level won't go up. However, this result shows that her liver and kidney do not function normally anymore. This is a very bad situation.

Son: Do you have the test result with you?

Doctor: Yes, here it is. So, this is the terminal stage. You may not want to believe this, but this is the stage just before death. Giving her treatments at this stage will be a burden for her.

[...]

Husband: What is happening to her leukocytes?

Doctor: At the terminal stage, they are always like this.

Son: Why does she have a fever?

Doctor: It is normal to have a fever just before death. In a sense, this is a natural process.

[...]

Doctor: Normally, when weakened, patients suffer from lower sodium, but in her case, the level has risen. It could be due to the Chinese medicine you have given her. At an intensive care unit, the sodium level would be urgently corrected, but it is meaningless to do that at the terminal stage of life.

Son: Is it really impossible, even if you try intentionally?

Doctor: Yes, if sodium is low, it could be supplied though...

Son: Are there any other problems with her blood test result?

Doctor: An enzyme level has gone up, too, but this is partly caused by her cancer.

Husband: I see. Thank you.

[...]

Son: Is there anything you can do about her unconsciousness?

Doctor: Well, it is caused by her cancer, so her unconsciousness won't relent unless her disease is cured, as I have been repeating...

Son: Oh... we should think about that, Dad.

In this conversation, scientific and medical terms, such as electrolytes sodium, leukocytes, and enzymes are frequently used. Despite this, the family's central concern is not very scientific. Reference to the patient's tumour itself and affected parts of the body are absent from the conversation. The family's main concern is at the molecular level, which is invisible without advanced technology. However, this invisibility is similar to that of *tairyoku.* In a sense, it seems that the family considers the patient's blood to be a flow of *tairyoku.* The fact that they still tried to make her take the Chinese medicine, and asked the doctor to manipulate the sodium level in the blood, may not be very different from the perspectives of other patients who try to rebuild *tairyoku* in order to fight their cancer. It can be said that this family also tried to put the patient's *tairyoku* back in balance by regulating her blood components, and to make it flow smoothly and harmoniously throughout her body. Although the word *tairyoku* itself was not used here, Mrs. Kaji's family members implied a similar concept in their desire to get something invisible back in balance for a better state of health. Additionally, it also seems that the family may have thought the patient would be cured if her blood components were in balance, or if she had better nutrition. It was thought that the patient's symptoms were caused by a decrease in *tairyoku* due to her inability to eat, rather than by malfunctioning organs due to her cancer. The subject of her cancer seems to be absent from the conversation.

1.6. *Tairyoku* and Western medicine

The collection of patients' and families' narratives demonstrates that traditional attitudes towards health and illness coexist with Western medicine within PCUs in Japan. The concept of *tairyoku* appears especially to be key. In sum, *tairyoku* functions as a measurement of bodily condition, and it is thought to have the power to cure disease. Therefore, activities to increase *tairyoku* are considered important, and eating is the prime example of this. When patients realize their disease is scientifically incurable, they attempt to increase their *tairyoku* to beat the disease this other way. Patients often believe that some medical treatments will result in a decrease in *tairyoku*, and thus reject them. They prefer eating foods or taking alternative medicine rather than undergoing Western medical treatments or taking drugs. However, when a decrease in *tairyoku* manifests itself despite their best efforts, patients will also turn to Western medicine in order to maintain the level of *tairyoku*.

Interestingly, then, when alternative medicine fails to meet patients' expectations, they tend to return to biomedical treatment. Ohnuki-Tierney (1984) has suggested that in Japan biomedicine is most effective in acute cases, and alternative medicine is most effective for health maintenance and in cases where biomedicine has failed. This may be because patients who are progressing to a more severe condition need more immediate and specific treatment. Biomedicine, which distinguishes between the body and mind, the physical and mental, the rational and emotional as independently constituted entities, can offer treatments specifically to meet patients' requests. It may also have more immediate and clearer effects than alternative medicine. (For example, it was explained to Mr. Hanazawa by his doctor that a drip infusion had calories equivalent to one rice ball.) Japanese patients may believe that

more specific and quick treatments on affected parts of body (including blood components in Mrs Kaji's case) will immediately result in returning the whole body to balance. This may explain why and how the Japanese holistic view of health and disease coexists with Western medicine.

In her book *East Asian Medicine in Urban Japan*, Margaret Lock (1980: 249) also shows how Japanese traditional medical thinking coexists with Western medicine. She mentions that traditionally in Japan, 'the social order is given and the individual should adjust to it' (ibid.: 249). Lock suggests that doctors and patients do not usually attempt to manipulate dimensions other than physical ones, even if other dimensions are seen as partially causal in the illness. Instead, doctors for example 'focus on building up the patients' physical states so that they can cope once again with the demands of daily life' (ibid.: 249). The work environment is considered unchangeable so the individuals are thought to be changed to cope with the problem. From the perspective of terminal cancer patients, the things happening to their bodies cannot be changed and should be accepted, as they know their disease is incurable. In order to adjust themselves to the situation, patients and carers want to change the patients' physical states, by building up their *tairyoku* level to cope with the problem, instead of manipulating the cancer itself.

The attitude of Mr Hanazono and Mrs Kaji's family described in the previous section may seem absurd and meaningless from the point of view of Western medicine, but is understandable in the context of Japanese concepts of health and illness.

1.7. *Tairyoku* – as a transitional narrative

For cancer patients, who have normally undergone aggressive cancer treatments, life at the PCU is considerably easier. Many patients experience much less

pain and symptoms at the PCU than before; however, this often leads patients to embrace unrealistic hopes or dreams. PCU staff hope that patients start as soon as possible to 'accept' the fact that they are dying, and prepare for it by carrying out unfinished tasks and hopes in order to die without regret (T Saito: personal communication, September 28, 2000). Contrary to this PCU staff's hope for patients, patients often seek to build up their *tairyoku* in order to kill the cancer, even though they are aware of the true diagnosis. When they realize that it is unrealistic to beat the disease, they at least attempt to maintain their *tairyoku* at a level where they feel comfortable. They initially make an effort to eat orally in order to increase *tairyoku* which they have lost due to the cancer. When they experience difficulty in eating, they start to seek medical assistance, such as TPN, in an attempt to sustain their *tairyoku*. As observed during my fieldwork, patients often try to take health foods bought from outside the hospital in order to sustain their *tairyoku*. Not surprisingly, the reaction of medical professionals to such behaviour is generally unfavourable. For example, I attended a meeting between a doctor, a chief nurse, the patient's husband, and her son, where they discussed the future care plan for the patient. During the meeting, the patient's husband mentioned that his wife was taking some health foods, including chitosan, which is widely known in Japan as a food that might improve the immune system. He asked whether this was a problem for the patient or not. The doctor said nothing, but the chief nurse answered, "When she becomes unable to eat it, she may get depressed." In this case, neither the doctor nor the nurse showed a positive attitude towards the patient's use of the health food, although they did not clearly dismiss it. The negative attitude on the part of the staff is probably due to the fact that such patients' behaviour cannot be approved by modern medicine, and also because the PCU is not a place where patients fight against cancer.

The attempt by patients to reach some sort of internal balance is usually continued until they finally realize that their *tairyoku* will only decrease until death, despite their every effort. Until patients reach this awareness themselves, PCU staff desperately try to influence their attitude. However, it is of course very difficult for PCU staff to tell patients to stop embracing unrealistic hopes regarding the power of *tairyoku*, and to suggest that they prepare instead for impending death.

The point at which patients realize that they are gradually losing *tairyoku* and cannot rebuild it again tends to indicate an acceptance by the patient that they are entering the terminal stage of life. Narratives concerning *tairyoku,* therefore, fill a transitional stage between the period of PCU admission and the final awareness of death (S Saito: personal communication, 2002). As mentioned above, the majority of medical professionals encourage patients to 'accept' their death as soon as possible so that they can spend their remaining days in a meaningful way. From such a perspective, patients' behaviours or narratives concerning *tairyoku* are often regarded as meaningless and are sometimes completely ignored[8]. However, given the fact that most patients I observed at the PCU appeared to believe in the fact that when their *tairyoku* could no longer be restored they were entering the terminal stage, it can be said that this concept is significantly important for patients in the process of dying. The concept of *tairyoku* has considerable meaning as a transitional narrative, and should not be ignored.

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[8] PCU staff commonly say that it is important for them to help patients not waste their precious time.

2. Good death and bad death

In this section, we will explore what kind of death is regarded as a good death in Japan. This will help to understand the issues of good death within the context of palliative care which will be discussed in chapter 6 and 7.

Namihira (1990), who investigates some particular ways to treat dead bodies and the memorial services for the dead, such as funerals, points out that in many parts of Japan, it was considered that there were two different kinds of death. One is 'unusual death or abnormal death' (*futsū de nai shi* or *ijō na shi*), and the other is 'normal death' (*futsū no shi*) (Namihira 1990: 47). Needless to say, it was thought that the former was an undesirable way to die, and should be avoided.

2.1. Unusual and normal deaths

Namihira (1990: 43; 1996: 169) presents unusual/abnormal death in Japan as: death in reverse order (e.g., an offspring dies before the parents), death outside the home, death by accident, death in childbirth, suicide, homicide, and death in a state of indignant anger. One of the features common to these occurrences of abnormal death is that it leads to the discontinuity of social units, such as a household.

According to Bloch's analysis mentioned in chapter 2, mortuary rituals are developed because people regard discontinuity caused by an individual's death as a menace to their society, and consider that death will spoil social values, the authority system, and key institutions which should be permanently maintained. Mortuary rituals are performed in order to remove this threat to continuity. The development of Japanese mortuary rituals implies that there was a common social value which was permanently maintained, and that this view was pervasive throughout society. Namihira (1996)

claims that this social value is represented by the traditional system of *ie* (literally means 'house', in the sense of a family household continuing in perpetuity)[9].

Continuity is an essential feature of the *ie*. 'The total membership includes all those who went before the ancestors, now forgotten as individuals, the recently dead who are remembered and the descendants as yet unborn. It is a duty of the living members at any one time to remember their predecessors, and to ensure that the house will continue after they die' (Hendry 1995: 24). Additionally, for the souls of the dead to become guardians of *ie*, it is considered necessary for their descendants to undertake rituals for them for a certain period after their death (Namihira 1987: 65). It can be said that for Japanese the most dreaded event was the loss of *ie* and carrying out such rituals for an individual was considered very important. Mortuary rituals have, therefore, been developed to guarantee the continuation of *ie*, and the succession of family property despite an individual's death. Death, which disturbs the *ie*, and which does not guarantee the continued engagement of the dead individual, is thus avoided. The reason why certain ways of dying are considered abnormal is because they disturb the normal succession of *ie*.

Therefore, features common to unusual/abnormal death in Japan can be summarized as follows. Primarily, death which leads to the disruption of *ie* should be avoided. Death, thus, should occur in the right order, from an older to a younger generation, for the smooth inheritance of the roles of the dead and the property of *ie*. Unexpected death by accident and death outside home are considered deleterious, probably since they do not allow the dying person to say his or her last words to his or

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[9] 'Multigenerational stem family that constituted the upper-class ideal during Japan's Tokugawa period (1600-1868) and served as the basis for the family legal code in the first half of the twentieth century. Ideally, an *ie* existed in perpetuity, with one married couple (or surviving spouse) together with their unmarried children in each generation comprising the living members of the household. The cultural preference was for the eldest son to

her heir; consequently, the proper order of the lineage is not maintained, and continuity is not guaranteed by the smooth transfer of authority. Death in childbirth is also considered bad, since the dead woman fails to contribute to the continuity of *ie*. The body of a woman who died in childbirth used to be cut at the abdomen in order to remove the foetus from the body before it was buried (Namihira 1990: 51). There is a folk belief that a woman who dies in childbirth becomes a monster called *ubume*. Namihira explains that this can be a punishment for the failure of fulfilling her social duty. It is said that the foetus is removed to prevent the mother from becoming such a monster.

Death which occurs violently or accidentally (due to accident, suicide, homicide, death in anger, and death outside the house) should also be avoided. It is believed that the soul of those who died suddenly due to violence or an accident does not go to the next world easily, since it is felt that they have died with regret or reluctance, and thus often some danger of misfortune may follow amongst the living (Namihira 1996: 170). For instance, it was believed that the soul of an individual who died outside home such as in the mountains would stay at the place of death instead of going to the next world. In order to get the soul back home, the family members used to go to the place of death after the body was sent home, and walked back home behaving as if they were carrying the body (Namihira 1990: 43). This was performed to take the deceased's soul back home, so that it could go to the world of the dead more smoothly.

The souls of those who died in an accident or in violent circumstances are thought to have a deep attachment to this world and hence remain in the world for a longer period. They are also believed to have a deep-seated grudge against the living.

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succeed his father as head of the household, and his wife to take on the responsibilities of the adult female role' (Long 2000a: 345).

This tendency is seen even more prevalently in those who died in anger. For these deaths, the intermediary period is very long; funeral rites are usually performed with greater care than usual. This means that it is believed that these souls are more vengeful and frightening than usual, and that they will bring misfortune to the living, unless greater care is taken (Namihira 1990: 45).

Another reason why unusual/abnormal death is detested is because it often results in the absence of the body. Namihira (1990) presents the following three points, reflecting on an airplane accident, which illustrate Japanese people's deep attachment to the body observed:

> - The Japanese bereaved families usually make the best effort to find and collect the body, even though the state of the accident does not allow them to discover the body (or the parts of the body) easily.
>
> - Although the majority of the bodies are badly damaged, and it would be psychologically devastating for the families to look at them, they are willing to confirm their identity with their own eyes.
>
> - The bereaved families long to visit the accident spot, namely, the place where death occurred, even though the place is dangerous to visit.
>
> (Namihira 1990: 20-21)

When dying, the person should be attended by many people, and after death, the body should be treated with great care by close relatives so that their soul can rest in peace. If the body is not found, the bereaved family finds it hard to accept death; moreover, it means that the body is abandoned somewhere without being properly looked after. Consequently, it can be argued that Japanese people visit the place where death occurred in an attempt to reproduce a normal death which is attended by family members. Additionally, their strong insistence on finding the body and taking it back home (even if badly damaged) is perhaps also because they attempt to reproduce the

normal death at home. For Japanese, the body is a significant entity for both the dead and the living. Japanese people believe that the soul of the dead cannot rest in peace unless rituals involving the treatment of the body are performed (Namihira 1990: 22).

As shown above, if abnormal death is marked as death that does not lead to the continuity of *ie*, which causes danger of misfortune, and particularly involves the absence of a body, normal death can simply be defined as death without these factors.

2.2. Desirable/ideal death and good death

What kind of death is considered particularly desirable, ideal, or good in Japan?

Lifton *et al* (1979) argue that dying well in the Japanese Buddhist tradition has usually meant dying quietly and without drama. There is meant to be an acceptance of death related to an acceptance of the cosmic order (Long and Long 1982: 2107). The Buddhist and Jungian scholar, Mokusen (1978: 37, cited in Wöss 1992: 73) argues that dying *isagi-yoku,* the *samurai* tradition of 'good death', is the Japanese approach to dying. *Isagi-yoku* means 'leaving no regret', 'with a clear conscience', 'with no reluctance'. Suzuki also regards the Japanese ideal as a death that is *isagi-yoku.* He quotes from the *Primer of Bushido*:

> The idea most vital and essential to the samurai is that of death, which he ought to have before his mind day and night ... when this notion takes firm hold of you, you are able to discharge your duties to their fullest extent ...
>
> (Suzuki 1959, cited in Long and Long 1982: 2106)

Long and Long continue that:

> The samurai, the kamikaze pilot, Mr Watanabe of *Ikiru* [Kurosawa's movie], all find meaning in action in the face of death. Continuing to fulfil social roles, keeping up the spirits of family and doctor by one's own cheerfulness or equanimity may represent similar opportunities of the common man and woman suspicious, if not certain, of impending death.
>
> (Long and Long 1982: 2106)

Mokusen demonstrates the ideal of dying *isagi-yoku* by describing the reaction of a Japanese friend when he was informed of his approaching death:

> He knew he was approaching death, and I found I could offer him no words of consolation. When we shook hands he said to me, "I am ready to go."
>
> (Mokusen 1978, cited in Wöss 1992: 74)

This man is ready to die without regret, and his equanimity may be expressed to keep up the spirits of his friends.

Dying *isagi-yoku* can also be the dying person's expression of consideration for those who have been giving care. By displaying no regret and keeping up the spirits of family and doctor by one's own cheerfulness and equanimity, the dying may feel that they impose less of a burden on those who have been caring for them. A calm death may relieve the family members, and the dying can feel as if he or she has in some way repaid the kindness received while being nursed. Additionally, since dying *isagi-yoku* means the departed had no regret in this world, the soul of the dead is considered to go to the next world smoothly and the living have little anxiety about the deceased's afterlife.

As shown above, dying *isagi-yoku* requires great strength of spirit. However, Long and Long (1982: 2106) point out that Japanese patients are dependent on their doctors and family members:

> Dr Alice Carey, an American physician who has practiced in Japan for 30 year, points out that in the U.S., cooperation with the doctor is based on the attitude that "We'll pull through this together". In Japan, expectations of doctor-patient relations lead to a more differentiated effort, with the patient expected to be emotionally as well as physically dependent on the physician.
>
> (Long and Long 1982: 2105–2106)

> Family relationship also illustrates the dependency expected of a patient. Dependency has been described as a critical aspect of all close family relations in Japan, and informants noted that dependence of elderly parents on their children for financial, emotional and physical needs is considered normal and desirable.
>
> (Long and Long 1982: 2106)

Many patients in Japan, therefore, are very dependent and have weak notions of an independent self, while dying a good death in Japan seems to be a lonely process, as it requires 'a strong self able to transcend the uncertainty of death and find meaning in it' (Long and Long 1982: 2106).

Some Japanese say that their ideal death would be *rōsui* (a gradual decline leading to death in old age) (Long 2001a; Long 2003). It is also ideal for Japanese people if an individual does not impose heavy burdens on the family when dying, and die *pokkuri* (die suddenly) (Long 2001a; Long 2003). In order to realize this, *pokkuri dera*—a type of temple where people pray for a quick and painless death at home without being bedridden, is popular especially amongst old people in Japan (Nakagawa 1997; Mori 1997; Long and Long 1982). Many old people who have finished their social duties think that they are a burden to the family, and dread not only suffering from disease and being bedridden for a long period, but also becoming an even heavier

burden due to illness requiring the family to look after them all the time. Therefore, it is common for old people to pray for a quick death[10].

Dying of cancer is, however, a challenge to both *rōsui* and *pokkuri*, as it is thought to be neither sudden nor pain-free (Long 2001b). Moreover, the concept of dying *isagi-yoku* is probably highly idealized and many lay people may find it difficult to achieve in real life. In fact, during my fieldwork I did not encounter many examples of dying *isagi-yoku.* Instead of dying *isagi-yoku,* I frequently heard people say that they wanted to die naturally or they wanted their family member to die naturally (die *shizen ni* or *shizen no mama ni*). Long (2003), who conducted fieldwork at a Japanese hospital, also heard this term often, and finds the term 'naturally' used in a variety of contexts. Firstly, "naturally' refers to a death that occurs without illness or societal responsibility' (Long 2003: 60). *Rōsui* and *pokkuri* are natural deaths in this sense. Secondly, 'natural' is regarded as opposed to 'medicalized' death. Natural death involves the least medical intervention to let nature take its course—no life prolongation and no emergency measures. However, it is important that pain is minimized and intimate human contact is maximized. Long (2003) relates natural death in this context to the concepts of *yasuraka ni* (dying comfortably and peaceably) and *shizuka ni* (dying quietly). Lastly, dying naturally means to live one's natural life span. Long (2003) argues that a combination of the second and third meanings of 'natural' dying constitutes the Japanese concept of the good death. Patients' following comments support Long's argument.

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[10] *Rōsui* and *pokkuri* are at one level in opposition to each other. Long (2001a), however, discusses that there are several themes that underlie both ideas: 1) a goal of a peaceful death; 2) the basis of such a peaceful death being that the last stage of life is pain-free; 3) that a good death is one in which the dying person is surrounded by caring family; 4) a recognition of a continuity from living through dying; 5) a belief that death is, or should be, a personalized experience appropriate to that person's values and life conditions; and 6) strong concern that one not become a burden on family.

> All human beings have a right to die peacefully. [...] I have lived for 67 years, so it is OK to die, but I don't want to have any pain.
>
> My doctor suggests that I have an operation for a stoma but I would like to go naturally until the end.
>
> I feel so relieved to be here [at the PCU]. I wanted to stay somewhere quieter [than the general medicine ward].

Many patients usually have great hopes of pain relief when they enter the PCU. In this sense, the hospice ideology of good death—'*saigo made sono hito rashiku*' (as myself, until the end) is more likely to be interpreted by the Japanese public as dying peacefully (*yasuraka ni*) or naturally (*shizen ni*) than as 'living' as myself until the end or 'living' as actively as possible until the end as the hospice philosophy advocates.

2.3. Good death and *tairyoku*

The concept of *tairyoku* helps to further understand why the Japanese public interpret the hospice ideology of good death as dying peacefully (*yasuraka ni*) or naturally (*shizen ni*) rather than as 'living' as myself until the end.

During my fieldwork, I heard that in the United States many cancer patients have a small cylinder which contains morphine implanted in the body so that they can live a 'normal' life as long as they want to. The attempt to import the cylinders for Japanese patients to use was turned down by a medical device company because of its unpopularity in Japan (M Teshima: personal communication, June 1, 2000). While patients in the States use a medical device to live well until the end, Japanese patients seem to try to firstly increase their *tairyoku* level in order to 'live well'. Having an implant operation and moving around actively may result in the decrease in their

tairyoku; therefore, Japanese patients prefer staying quietly in bed and devote all their time and energy to increasing *tairyoku*. This explains why some patients I observed did not want to go back home for a few days unless they have no symptoms at all and feel perfectly well (see chapter 5 for examples).

Moreover, 67-year-old stomach cancer patient said the following when he was asked by his doctor if he has something he would like to do during his stay at the PCU;

> Nothing. I have sorted everything out already. [Then the doctor asked if the patient wants to go to a hot spring.] No, it is not because I am afraid of death, but because I wouldn't enjoy it while worrying about pain and fever. Since I foresaw [my death] I have only been thinking how to die peacefully.

For this patient, it seems that living as actively as before until the end (i.e., going to a hot spring) does not mean dying peacefully, and he seems to believe that he cannot die peacefully if he has even the slightest symptoms and pain. The most important thing for him to die peacefully is to have no symptoms and pain at all. It can be assumed that for him any activities which may cause pain should be avoided in order for him to die peacefully. In fact, this patient stayed at the PCU throughout until his death, even though the PCU staff suggested him a number of times that he should spend more fruitful time with his family elsewhere.

Japanese patients tend to stay at PCUs throughout until they die rather than to live as themselves until the end. This is not because their attitudes towards life are passive. They still actively challenge cancer by coping with *tairyoku*; however, when they realize that their *tairyoku* level starts to decrease and it is not amendable by any means, they would like to let nature take its course. This is probably the way to die a natural and peaceful death for many Japanese patients. As seen in the case of Mr

Hanazono; however, when patients realized the decrease in their *tairyoku* while they are still physically far from death, they have to suffer from despair for longer. This exhausts not only the patients but also the carers and the PCU staffs.

3. Summary

Patients who experience a considerable decrease in pain and difficult symptoms at the PCU typically start to embrace unrealistic hopes of recovery, against PCU staff's expectation. Instead of 'accepting' death, they attempt to revive *tairyoku* to its normal level. Narratives regarding *tairyoku* can regularly be heard—until patients finally give up the attempt to increase its level. Although their narratives regarding *tairyoku* do not medically make sense all the time, they play an important role for the patients to accept death and should not be made light of. The concept of *tairyoku* also explains the Japanese patients' attitudes towards the dying process and the reason why many patients prefer to stay at the PCU rather than to lead an active life.

In the next two chapters, we are going to look at PCU patients' dying process. I would like to examine how the dying process at PCUs plays a role of a transitional period before funerals where rites of incorporation are conducted. We shall also investigate the treatment and care that patients receive during this period.

Chapter 5: Becoming a Patient at the Palliative Care Unit

In the following two chapters, I will look at the dying process of patients who are receiving treatment at a palliative care unit in Japan with a special emphasis on ascertaining whether the period of dying process plays a role of separation and transitional period before the funeral during which rites of incorporation are conducted. I will divide the process of dying into two stages—admission to the PCU and the period of stay at the PCU. These are defined as the stage of separation and the stage of transition respectively, in accordance with van Gennep's notion of the rites of passage.

In this chapter, the first stage of the dying process, the stage of separation (admission to the PCU), will be examined. I will look at how individuals abandon their social identity and become PCU patients and how they come to terms with their situation. This will be followed by examinations of the process of losing one's sense of self—social dying.

1. Admission to the palliative care unit

The typical ways in which a patient is admitted to palliative care unit (PCU) are: transferral from a general ward or other wards to a PCU within the same hospital; transferral from another hospital; or admission directly from home or from an outpatient clinic (The Japanese Association of Hospice and Palliative Care Unit 2000:

28). The reasons for PCU admission are the patient's own desire, family recommendation, or doctor's recommendation. According to the Japanese Association of Hospice and Palliative Care Unit (2000: 28) it is more likely that patients themselves will decide to enter into palliative care these days. This is probably because more people have acknowledged the existence of such institutions, and also because more patients are now being told the true nature of their illness (The Japanese Association of Hospice and Palliative Care Unit 2000: 28). On the other hand, there are still some patients who hesitate over moving to a PCU. This may be mainly because some patients still think that they will die sooner if they enter care[1]. The PCU staff, therefore, explain to patients that they can still receive treatment[2], that some patients even come out of the PCU, and that there are professionals who control pain and other symptoms (The Japanese Association of Hospice and Palliative Care Unit 2000: 28).

During my fieldwork, I attended many PCU outpatients' consultations, where it was discussed whether a patient needed to enter a PCU or not. The most important point in these discussions was always whether or not patients would like to continue curative treatment for their cancer. For example, on one occasion I observed an outpatient consultation where a doctor saw a patient with tongue cancer. The patient had previously received an intensive course of radiotherapy treatment at Hokkaido University Hospital. During the consultation, the doctor said to him:

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[1] Among ordinary Japanese people there still seems to exist the belief that hospice/PCU is merely the place where the very terminal patients wait to die rather than the place which provides patients with pain relief and encourages patients to live until the last hours.

[2] Treatments that PCU patients can receive are mainly associated with pain relief. However, if patients wish, they can undergo less aggressive curative treatments than those given at a general ward. Radiotherapy is such a treatment. The aim of the treatment which PCU patients undertake is not to cure or to reduce the size of the tumour, but to slow down the progress of the disease or to relieve pain.

If you decide not to have any more curative treatments, it is good to enter here, but if you still want to try to cure it, I think Hokkaido University Hospital [which is more cure-oriented] is better for you...

The following is a conversation between a PCU doctor and another tongue cancer patient who was hospitalized at the time in an internal medicine ward at Higashi Sapporo Hospital:

Patient: Whether or not I should move to a PCU is a problem that will affect my entire life, so I would like to consider it carefully. At the moment I don't have any pain at night, and I think I should try more curative treatments. I think this is another way...I would like to try the most advanced treatments for a week or 10 days...

Doctor: Well, sooner or later you should decide whether you would like to continue curative treatments or not. Roughly, you will have to decide if you would like to prolong your life using curative treatments or if you would like to lead a comfortable life regardless of its length.

After all, this patient decided not to move to the PCU, as he still wanted to continue curative treatments in order to live longer.

The following is part of a conversation between a PCU doctor and a breast cancer patient who had recently moved to the PCU from a surgery ward within Higashi Sapporo Hospital. After a medical examination and interview, the patient said to the doctor:

> I think I tried all the possible curative treatments. My pain, however, got worse. My doctor [at the surgery ward] said to me that he was not sure if the pain could be relieved any more. He said, to be frank, nothing could remove the pain. Then I thought that I had nothing to do there any more. I did try all the pain relievers and anticancer treatments. I have seen some patients dying. I chose this ward [PCU], because I realized there was no medicine which would work well for my cancer. I did not want to have any life-prolonging treatments.

The crucial factor in deciding to enter a PCU is whether to continue curative treatments or not. It is preferable that patients themselves make this decision. But in the case of patients who are not aware of their true diagnosis, family members take an important part in the decision making process. For example, a seventy-five year old female patient was not told that she had lung cancer. Because she was old and her disease had already reached a fairly advanced stage when it was first diagnosed, her family decided not to tell her the truth and hoped that she would not have to undergo any curative treatments, which usually causes much physical pain and discomfort. In this patient's case, it was her family who decided to send her to the PCU. There is another case of a seventy-nine year old female cancer patient. She was not told that she had cancer, but that she merely had a tumour. She did not wish to undergo any painful treatments, and thus her family suggested that she move to the PCU, telling her that it was a famous place for pain relief.

Whether the decision has been made by the patient themselves or by family members, it seems to be very important for PCU staff to make sure that patients and their family acknowledge the aim of the PCU, namely, that it is not a place for cure. Otherwise, some patients and families may subsequently complain about the

treatment they are able to receive at the PCU. In other words, agreeing to the PCU treatment policy is an important step in the initiation process before entering a PCU.

Once they decide to enter the PCU, all patients have a consultation or an orientation meeting with their doctor, nurse, and a medical social worker at the PCU. This usually takes place in the patient's room with his or her family present. Almost all patients had already experienced aggressive curative treatments before entering into palliative care[3]. At the initial consultation, the doctor once again emphasizes the policy that PCU staff are more engaged with pain and symptom control than with curative treatments. Then the doctor gives a medical examination by interview. Typical questions are whether a patient has general malaise, anorexia, nausea, bowel movement, dyspnea, insomnia, and depression. Then the topic moves to the main concern, pain and symptom control. The doctor listens to the patient's complaints carefully and suggests possible methods to control them, explaining both the positive and negative effects, so that the patient can choose the best method for him/herself. The doctor usually asks the patient about his or her background and about other concerns or anxieties.

The following is part of a conversation which took place at an orientation meeting between a doctor and a new (male) patient with cancer of the pancreas:

> Doctor: Before you were told the true diagnosis at NTT Hospital on March 6th, had you ever thought about anything...?
>
> Patient: Yes, since many members of my family have had cancer, but...
>
> Doctor: Possibly yourself, too...?
>
> Patient: Yes, I thought so.

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[3] During my fieldwork in Higashi Sapporo Hospital, I observed only one patient who was directly sent to the PCU by his former doctor at another hospital without having been given any curative treatments. His cancer was obviously too progressed for anything to be done for a cure.

Doctor: Do you mean you were not shocked very much?

Patient: Yes. I expected I would have become more depressed. I had been living alone, so I had been thinking I would die from cancer somehow…Anyway, I didn't get depressed. The year before last, my brother died from cancer, too. He underwent an operation, but he was not saved. It was very shocking.

Doctor: Was that more shocking? How about after March 6th? Did it [the diagnosis] give you a shock later?

Patient: Well, I have heard that cancer of the pancreas is very painful, so I have been thinking it will be horrible…, and I am worried about my house and my children.

Doctor: Oh, well…

Patient: I am worried about my car and my children rather than my own death. It snowed so much the other day, didn't it? I have been worried about my car since then.

Doctor: Here we try to relieve patients' pain and uncomfortable symptoms. However, if you prefer, you can also stay at home. Your house is not too far from here…You haven't thought about that because you live on your own?

Patient: (nods)

If a patient's family attends the orientation meeting, the doctor usually asks family members to convene to another room, where he gives them a more detailed explanation. This usually contains negative information, such as more precise prognosis[4] or information relating to the side effects of treatment.

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[4] Doctors usually give rather ambiguous prognosis to patients. For example, they may say to a patient, "You may not be able to have a yearly plan", while they say to the patient's family, "To be honest, I don't think he [the patient] can live more than three months."

2. Separation from society

In this section, we will explore the implications of becoming a patient in the context of palliative care.

2.1. Abandoning social identity

During my fieldwork, I encountered many patients who said that the diagnosis changed their life totally. For example, one patient who was a cook and owned his own Chinese restaurant handed over his job to his son when he learned that he suffered from advanced cancer. Upon being diagnosed with liver cancer, another patient sold all the stock certificates he had. He also told his family that he wanted to sell his land in Kitahiroshima city, which is next to Sapporo, to build a house in Sapporo, as it would become easier for him to go back home when he entered the PCU at Higashi Sapporo Hospital. In this manner, the knowledge of having cancer usually stops patients from continuing to live as before. In other words, at the time of cancer diagnosis, they abandon the social identity which they used to have when they were healthy.

2.2. Social isolation

When they finally enter a PCU, patients typically avoid seeing people other than their family members. One patient who was a president of his own company told medical professionals that he did not want to see anybody from his company as he looked so weak and fragile. In fact, only his wife and sister visited him to take care of

him. Another female patient, Ms Shintani[5], stopped seeing her boyfriend. In fact, as soon as she found out that she had breast cancer, her boyfriend stopped contacting her. Although her mother insisted that she should call him from the PCU, she never did. She also avoided receiving calls from any of her friends, mainly because she could not talk properly due to her cancer symptoms. Other than her mother, her brother and his wife who lived in Sapporo visited at weekends, and a sister, married and living in Nagano Prefecture, came to see her whenever she could take holidays. One friend who frequently visited was a woman whom Ms Shintani had met when she was in a general ward at Higashi Sapporo Hospital. The woman was also suffering from breast cancer, but hers was so minor that she did not have to enter a PCU. It seemed that she was the only person that Ms Shintani could talk to in any meaningful way about her disease[6].

Some patients chose Higashi Sapporo Hospital mainly because it was so far away from their home that they could conceal their PCU admission and avoid seeing acquaintances. Some patients said to medical professionals on their PCU admission that, "Here I can be more relaxed without worrying about the public eye." With the increase of people who die from cancer every year, it can be assumed that there is much less stigma about cancer than before. However, many cancer patients still tend to hide themselves from others' eyes. For example, at the PCU, there was a 59-year-old male patient with lung cancer who used to be a managing director of a company. He only allowed his family and his wife's sister to visit him at the PCU,

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[5] Ms Shintani is one of the patients I saw routinely, from her PCU admission until I left Higashi Sapporo Hospital for Oxford. She was forty-one at that time; suffering from breast cancer. She was not married, and her mother who was in her seventies was her main carer. More details on Ms Shintani will be given in chapter 6.

[6] Although I saw Ms Shintani almost every day for eleven months, she seldom talked about her disease to me. Even when I specifically asked her about it, she never looked willing to talk. Her mother also told me that she had never discussed her daughter's disease thoroughly with her.

and strictly declined to see any other visitors, as he did not want to be seen in his weak condition and to appear entirely different from the one before their illness.

2.3. Social uselessness

Many patients also suffer from the feeling of social or familial uselessness. Being at a PCU prevents patients from performing their previous social roles. Furthermore, physical deterioration makes them more dependent on others, and patients may feel not only that they are useless, but also they are a burden and trouble to their family. The physical deterioration of cancer patients only worsens until they die, and there is no chance for them to repay carers' kindness or to return to the society to which they used to belong. The physical deterioration also accelerates patients' embarrassment and increases the need for isolation.

2.4. Hospitalization and identity

The Japanese anthropologist, Ohnuki-Tierney (1984), suggests that hospitalization in general does not remove patients from society in Japan. This is because each patient continues to be a *person* by using personal belongings during hospitalization (e.g. pyjamas), to be a *kin member* by being cared for by the family, and to be *a member of a larger social group* by receiving visitors from work. She continues:

> In fact, during hospitalization, these roles are tested and hence even more clearly articulated than usual. As a patient's social network becomes intensely activated, the social definition of the patient's self, as defined by multiple roles in the network, becomes clearly accentuated. In other words, the patient is not removed from the society; on the contrary, the patient is given an opportunity to feel and experience both individual and social identity, as well as importance as an individual and social persona.
>
> (Ohnuki-Tierney 1984: 214)

While it can be argued that general hospitalization does not remove patients from society in Japan, the nature of cancer and the meaning of palliative care usually render patients unable to maintain their social identity at PCUs. Generally at PCUs, patients are also encouraged to use their own personal belongings and to be taken care of by family members. There is even a special room for families to stay overnight, and the PCU has very flexible regulations for visitors. Nonetheless, as mentioned above, almost all the patients I observed preferred not being visited by anybody whom they used to know when they were healthy. At the same time, those who used to know a patient may find it difficult visiting them at the PCU. Ohnuki-Tierney emphasizes the importance of visitors, who enable patients to maintain their social identities; however, unlike general hospitalization for more minor diseases, it is very difficult for cancer patients to maintain their previous social identities at a PCU. Losing these social relationships is the beginning of a process which leads ultimately to the social death of the patient prior to the biological death.

2.5. Rites of separation

The most important point to discuss at admission to the PCU is whether or not patients would give up pursuing curative treatment of their cancer. Only patients who decide not to receive any more curative treatment will enter the PCU. This means that at admission to the PCU, patients admit that they are in the process of dying. The decision, therefore, separates them from normal social life in which they used to be, and in this sense, it can be argued that making a decision to enter the PCU is a rite of separation.

After this separation rite, many PCU patients experience a sudden void in their self-perception; they become reduced to a mere individual with no social involvement. They also suffer from their perceived uselessness, and thus PCU staff devote themselves to assisting patients to live, not only without feeling empty or useless, but also to live as actively as possible.

This is an interesting contrast when considering that rites of separation usually involve bond breaking rituals (see chapter 3, section 1.1). At the PCU, on the one hand, patients are asked to give up pursuing cure in order to survive and expected to accept death as soon as possible. They are, however, at the same time asked to maintain their social self and to live as actively as before. Instead of breaking the bond to separate patients from healthy people, at the PCU patients are encouraged to deepen the bond with their family members and to maintain their life as before as much as possible. This inconsistency in policy has inevitably caused some difficult situations for both medical professionals and patients. The fact that patients' physical condition is usually improved due to pain control at PCUs is also part of the cause.

One of such problems is fostering false hopes in patients, as described in the next section.

3. False hope

At PCUs the removal of pain and uncomfortable symptoms is of prime importance[7]. Therefore, the most dramatic change which new PCU patients experience is a significant reduction of pain and symptom. Almost all patients would have undergone aggressive curative treatments before entering the PCU; however, the treatments given at the PCU are not at all like that. Alleviating pain apparently makes both the patients' physical and emotional condition better, and this changes not only their attitudes towards themselves and their illness, but also their belief in the possibility of recovery. We will now discuss these aspects using examples from my field observations.

3.1. Case study (1)

A thirty-six year old female patient with cancer of the uterus (Ms Yasukawa)[8] told me:

> At the previous hospital, I had a course of radiotherapy on my neck. I lost hair. My body got so stiff and I could not move. I was even thinner then than I am now. It has been one year since then. [...] I am now such *genki* (literally means good health), and my complexion is much better.

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[7] In fact, pain and symptom control is the major reason given by those patients who seek to enter palliative care. The other reasons are: (1) they want to have a quieter environment; (2) they need more meticulous care; and (3) they want more psychological or spiritual care, which they usually do not expect to receive in other wards.

[8] Ms Yasukawa is another patient I saw regularly at the PCU.

> Before coming here, I was so thin, and felt dizzy. My body didn't move. I had a bald head. I could move only my eyes, and I thought I was going to die soon.

Ms Yasukawa was very pleased with her condition and with her quiet private room at the PCU. Since she became more *genki*, she was able to eat more and to go home more often to see her five-year old son as encouraged by the PCU staff. She then started to dream of attending her son's entrance ceremony to a primary school, which was impossible considering the condition of her disease. In fact, it was very painful for both the PCU staff and myself to listen to her talking about her hope[9].

The case of Ms Yasukawa highlights that the positive consequences of treatment at the PCU and the staff's encouraging attitudes towards her created unrealistic expectations in patients; what we may call 'false hopes'.

3.2. Case study (2)

Despite the knowledge that they are suffering from an incurable disease, many patients start to believe that the cancer is even being cured due to successful pain control. One female patient said to her doctor on his round:

> Doctor, I am really getting better. I am trying hard!

On another occasion, she again told her doctor that she was so pleased with her condition. The following conversation took place in her room in the presence of her doctor, nurse, and medical social worker.

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[9] Unfortunately her dream was not realized in the end.

Patient: I feel so much better now. I cannot think of how bad it was when I entered the PCU. My husband came here yesterday, and he was so surprised to see me like this. He said, "God, you look much better. What a surprise!" He was so pleased, too.

Doctor: Your hope on your admission was only to have your pain removed, but what is your hope at present?

Patient: I can't say anything more. Otherwise, I just have more and more hope… Thank you very much indeed.

Doctor: Your first aim has been achieved. Well, what do you want to do next? I remember you wanted to go home sometime.

Patient: Yes, when it's cured.

Doctor: Well, what do you mean by 'cured'?

Patient: I mean, when I have no numbness.

Doctor: I want to talk about that. Is it OK for you to discuss it now then?

Patient: Yes… I know I have persistent cancer.

Doctor: Your numbness is caused by the cancer. As it is impossible to throw off cancer, your condition cannot be any better than this. It is hard to get rid of the numbness.

Patient: I know it will take a long time.

Doctor: It does not take a long time, it is incurable.

[…]

Patient: How about just suppressing the power of the cancer?

Doctor: Suppressing is also impossible. Any treatments, including an anti-cancer treatment, are also meaningless.

[…]

Despite her knowledge of having a fatal disease and the fact that she entered a PCU where she would not undergo any curative treatments, pain relief caused this

patient to foster the false hope that she was recovering from cancer. Medical professionals tend to hope that patients will start to accept death as soon as it is found out that their cancer is incurable; therefore, patients at the PCU are not encouraged to have this kind of hope[10]. However, my fieldwork proved that many patients started to embrace unrealistic hopes, and that they did not smoothly transfer their feelings towards the so-called stage of 'acceptance of death' immediately after PCU admission. As discussed in chapter 4, the concept of *tairyoku* plays an important role in this process as a transitional narrative.

4. Summary

Within the framework of Van Gennep's 'rites of passage', admission to a PCU can be called the stage of separation. On admission to a PCU, patients become separated from the society to which they used to belong. Retirement from previous work, selling assets, and sorting out one's belongings are all examples of separation rites which help patients break bonds with their former social activities. Moreover, some patients even choose a particular PCU partly because it is far away from their home, so that they can avoid being involved with people whom they used to see when they were healthy. Whatever the reason for entering a PCU, patients and their family members have to agree with the PCU treatment policy on admission; namely, that the intention is not to cure cancer, but to focus more on pain relief in order for the patient to spend the rest of their life as comfortable as possible; therefore, patients should

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[10] In many cases, doctors have a meeting with patients called 'modifying the prognosis meeting' in order to help them realize the fact that recovery is unrealistic Doctors believe that this will help patients carry out as many things as possible before their last day. The aim of this meeting is, therefore, not to let patients down. It is essential to give patients the true prognosis and to help them establish a new hope which is possible to realize within their limited physical ability and time.

give up seeking curative treatment for their disease. This implies that patients will not return to the society to which they belonged when healthier. The moment this decision is made can be called an initiation into the dying process, being separated from 'normal' life and 'healthy' people.

In this way, PCU patients go through the stage of separation on admission to a PCU. In reality, however, this does not proceed smoothly. Based on the hospice philosophy, the staff encourage the patients to maintain their social identity in order to enable them to live as actively as possible. They also encourage the patients to deepen the bond with their family during their stay at PCUs. It is interesting to point out that the stage of separation at PCUs are different from the separation stage seen for example during funerals in old Japan, where bond breaking rituals are main activities and the dead are strongly inhibited from retaining attachment to this world. Once separated, the soul of the dead was considered never to come back to this world. It can be said that in the context of palliative care, the stage of separation has been changed into a new form. My field observation, however, proves that this 'new form' does not function rightly. In fact, this has created much confusion for both PCU staff and patients.

The prime concern of palliative care—pain and symptom control further contributes to the confusion. Successful pain control helps patients maintain their previous social identity after their PCU admission and establish a meaningful relationship with their family. Pain control is one of the aims of the hospice philosophy, but patients whose pain is successfully relieved are typically not only able to retain their identity and to deepen the bond with their family but also tend to embrace unrealistic hopes of recovery. Although the PCU staff desire the patients to live as actively as they used to before and to enjoy a good time with their family, they

do not expect the patients to think they are getting better; they expect them to 'accept death' as soon as they enter the PCU. Patients are, on one hand, expected to live actively, but on the other hand, expected to be ready to die at the same time. It is easy to assume that the stage of separation at PCUs is very confusing in practice due to these two incompatible expectations towards patients.

My field observation proves that many patients find it difficult to meet the PCU staff's expectations, and in fact the longer the patients stay at the PCU, the more they find it difficult to perform as expected, mainly due to physical deterioration with the advance of cancer.

In the next chapter, we will look at the dying process of the PCU patients, who are in the transitional period between the stages of separation and incorporation within the framework of van Gennep's rite of passage. I will examine the gap between the reality and the hospice philosophy of 'good death' by describing patients' experiences of dying process at the PCU.

Chapter 6: The Dying Process at the Palliative Care Unit

Chapter 5 described that it is not easy for the PCU patients to go through the stage of separation. At the PCU, patients are typically placed between two incompatible expectations; to accept death as soon as possible and to live as lively as possible as before while deepening the bond with their family. With the help of pain control, many patients even start to foster a false idea of recovering from their cancer against the PCU staff's hope—the staff expect the patients to prepare for imminent death as soon as possible.

Those who failed in understanding their real situation at the stage of separation inevitably face the reality in due course. When this happens, are they still able to maintain their social identity? Are they also still able to 'live as themselves'?

In this chapter we will look at the dying process of patients who are, within the framework of van Gennep's rite of passage, in the transitional period between the stages of separation and incorporation. In order to answer the questions above, I will examine three case studies based on my field observation. In so doing, I will also demonstrate what kind of death is considered good and bad at the PCU and examine factors which prevent the PCU patients from dying a good death.

1. Case studies

In this section, I will give three case studies regarding the way of dying. In the first case, the patient realised that he was no longer able to throw off cancer when he started to lose *tairyoku* in spite of all his efforts to increase its level. Since then, he started to only wish to die. The second case shows that the patient switched herself off when she learned that she would not be able to walk on her own again. In the third case, the patient lost her desire to live once she learned that her prognosis was not as good as she had expected. The characteristic common to all the cases is that the patients die socially long before their physical death.

All the cases I introduce in this chapter are significant because their dying processes represent many patients' experiences at the PCU, although these three cases are somewhat extreme. None of these cases was considered as a good death by the PCU staff; they were even considered bad by some of them.

1.1. Case study (1) - losing *tairyoku* (Mr Hanazono)

As explained in chapter 4, the concept of *tairyoku* plays an important role as an intermediary narrative between the period of PCU admission and the patient's final awareness of death.

Here, I would like to return to the case of Mr Hanazono (see chapter 4). This case demonstrates that the awareness of losing *tairyoku* can be a factor which leads a patient to social death. Mr Hanazono's case is remarkable in the following respects: firstly, although he knew his true diagnosis, he still believed that improving *tairyoku* would cure his cancer; and, secondly, this is the only case where I observed that the

family members treated the patient as if he was already dead, once the patient admitted that he was going to die.

Mr Hanazono was an 85-year-old Christian, who had parotid gland cancer. He was admitted to the PCU at Higashi Sapporo Hospital on 4 January 2000. Despite his old age, he was proud of his young looking and healthy lifestyle. Before his cancer was diagnosed, he had energetically enjoyed a number of activities with younger people, such as skiing, dancing, climbing mountains, and so on. Even after being admitted to the PCU, he carried out a regular leg exercise using a walking machine in the hospital. He believed that increasing the level of *tairyoku* is most important to 'cure' cancer, and in order to increase its level, he not only tried to exercise regularly but also to eat health food.

Despite his optimistic view, Mr Hanazono's disease was progressing. His doctor was concerned about the possibility of a haemorrhage, which could be lethal. The doctor was thinking that Mr Hanazono should go home as soon as possible in order to spend some good time with his family at home. Mr Hanazono, on the other hand, did not wish to do so. As he was trying to 'cure' the cancer, going back home was not a good choice. Ignoring the medical staff's concern, he was devoting himself to rebuilding *tairyoku* by eating health foods and exercising.

By the end of February, he started to have general malaise and difficulty in breathing, which made him realize that his disease was progressing, and the level of *tairyoku* was decreasing in spite of all his efforts and even medical assistance. By this time, he seemed to admit that he was dying, not recovering after all. In fact, a nurse reported at the staff conference that she found that Mr Hanazono was drawing up a will. She asked him when he had started, and he answered that it was about two weeks

before then. This surprised her because around that period Mr Hanazono looked like he was still trying to get better by rebuilding *tairyoku*.

Since then the conversation topics between Mr Hanazono and his doctor had completely changed. Although he used to talk to his doctor about some miracle stories of people who had recovered from cancer, he started to say that he had done everything he wanted to in his life, so he would like to die soon. At a doctor's round on 25 February, he said to his doctor, 'I would like to leave my body to medicine'. He also said, 'I have no regret. I just don't want to suffer when dying'; 'How am I going to die?'; and 'I have been doing yoga just because I wanted to die while I am able-bodied, or wanted to die *pokkuri* (suddenly), but why do I have to suffer from cancer?'

At a staff case conference on 2 March, the doctor in charge reported that Mr Hanazono hoped to have euthanasia practiced on him, once he realized that *tairyoku* could not cure cancer. Although Mr Hanazono was given sedatives intermittently, every time he woke up, he asked the doctor to terminate his life, and also asked his family members (his three daughters in their forties) to pray that God might take him to Heaven. His daughters all pitied him in his situation. The medical social worker reported that Mr Hanazono had said goodbye to all his close friends and relatives, as both he and his family believed that he did not have many days left before death. One of his daughters even forced her teenage son, who was studying in the Unites States, to come back home to say farewell to Mr Hanazono. On 1 March, a nurse reported in the medical record that Mr Hanazono got so displeased with a tube of continuous subcutaneous infusion that he shouted and said, "Give me scissors! I want to cut this off. I don't need it!!"

Medically speaking, however, his condition at that time was still far from approaching physical death. He could even walk to the toilet without any assistance. This was the reason why the PCU staff did not agree to the request from Mr Hanazono and his daughters to carry out terminal sedation[1], which takes consciousness away from the patient until he dies. His daughters were not pleased with the staff's decision, and said to the doctor:

> He really wants to be relieved from the whole situation. I can't see the point that he should be awake.
>
> He knows he won't recover. Under this situation, even if he could have a good time with the family, I doubt whether it is really a good time for him.
>
> I don't think he needs either a time to be awake or a 'good' time with his family.
>
> It is not important for me to talk to my father when he wakes up between sedations. I feel so sorry for him. My memory of my father is only how I remember him when he was healthy. I do not want to remember anything about him after the admission to the PCU.

Although Mr Hanazono's three daughters gave comments like these unanimously, his wife showed a very different attitude and view toward Mr Hanazono. She said that when she was with Mr Hanazono, he never said anything negative to her. Instead, he asked after his garden trees at home, and talked about some food he would like to eat. Therefore, Mr Hanazono's wife did not agree to the idea of giving him a terminal sedation at this point. Her opinion was, however, not taken seriously by the daughters who said to her, 'You are with him only when he feels better' and 'He is just trying not to worry you'.

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[1] More detailed accounts for sedation will be given in chapter 7.

On the morning of 4 March, Mr Hanazono woke up from the intermittent sedation, yet he only kept saying to his family, 'I want to die. I want to go now' and 'It's time to say goodbye. Sing hymns for me'. Heavier sedatives were given to him in the afternoon. He never woke up again after that, and died in the morning of 6 March.

Mr Hanazono abandoned his social identity at admission to the PCU. Especially because his disease affected how he looked, he refused to see anyone other than his family members; he ceased to be the person he had been when healthy. At the same time, however, Mr Hanazono was or looked very optimistic about his diagnosis, believing in the miracle of *tairyoku.* Yet, he was also making his will during this time, which means that he may have known that his *tairyoku* would not cure cancer. Probably doing something positive and hopeful was the only way for him to be able to maintain his sense of self.

The PCU staff were considerably relieved when Mr Hanazono stopped talking about curing cancer by increasing *tairyoku.* All the staff understood that Mr Hanazono had finally 'accepted' death, and started to look at the reality of the situation and to foster new hopes, such as returning home to have a good time with his family for the last time. Instead of appreciating the reminder of his life, however, Mr Hanazono started to hope to die immediately. He said farewell to all his family members and friends, then 'switched himself off'.

His daughters later reflected that he had significantly changed after he realized his imminent death: 'He was not as he used to be'. Notwithstanding the fact he was alive, he was socially dead. His three daughters found it so distressing to see their father like that, and kept asking the doctor to let him 'sleep'. Actually, according to the medical record, the daughters were very upset and shattered by the way their

father behaved, every time he woke up from intermittent sedation. They simply did not know what to say to him.

At a staff conference after his death, Mr Hanazono's case was examined. The medical social worker suggested that Mr Hanazono's 'bad' death had occurred because the process of informed consent was too short. As the PCU staff did not want to deny his hope for cure completely, it was difficult for them to bring up any topics about the truth (i.e., the fact that he was dying and his disease was only getting worse every day) when they talked to him. They were trying to find the best moment for him to discuss such topics together, but consequently they missed the chance. As discussed in chapter 4 the concept of *tairyoku* played an important role for Mr Hanazono to understand that he was entering the terminal stage of life. However, it seems that Mr Hanazono could not accept himself as a dying person, and when he became fully aware of death, he socially died.

It seems clear that part of Mr Hanazono's distress stemmed from the fact that he could not die when he wanted to: in other words, it was tragic for him that social and physical death did not happen simultaneously. It can be said that Mr Hanazono involuntarily tried to shorten the period of time between social and physical death by requesting heavy sedation, as this puts a patient into an 'eternal sleep' while he or she is still alive. Lawton (2000: 132) also shows a number of examples of hospice patients who requested heavy sedation, euthanasia or refusing to eat or drink. Lawton suggests that those patients sought such external aids to achieve a complete withdrawal and to become a 'non-person' who has no capacity at all to act and to interact with others (ibid.). In Mr Hanazono's case, he and his daughters requested heavy sedation in order for Mr Hanazono to 'sleep forever'; therefore, I would say that sedation was recognized as a means to advance his physical death. In any case, I suppose that those

patients who request such external aids are frightened to be conscious enough to face the number of sufferings, including hopelessness and uncertainty, they would otherwise experience during the dying process. It is, therefore, ideal for those patients to lose consciousness until the final day.

It is also ideal for the carers if the patient loses consciousness before they die, since then they do not have to feel helpless when they see the patient in agony. The heavily sedated patient who sleeps peacefully saves the carers from an emotionally draining experience which they would have to go through otherwise. The following statement, which was made by one of Mr Hanazono's daughters to the doctor, highlights this kind of attitude.

> It would be great if one could control his own death by himself. It would be so good if one said farewell to others, and then died while sleeping without becoming a burden to a family.

The hospice philosophy stresses the importance of the patient's autonomous attitude during the dying process. However, in reality, it is impossible for the patient to decide how and when to die. Heavy sedation was given to Mr Hanazono in the end, but the timing was decided solely by his doctor. Before then, in accordance with the hospice philosophy, the PCU staff put much emphasis on finding a new hope for Mr Hanazono to live for[2]. Mr Hanazono's dying process was like a tug of war between the PCU staff and Mr Hanazono and his family who were trying to push back social death until the moment of physical death and who were trying to bring forward his physical death ('sleep' by sedation) respectively.

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[2] Mr Hanazono's case was repeatedly discussed at the PCU staff conferences as an example that not only the patient himself but also his family could not face and accept the reality. Instead of hoping to spend as long time as possible with the patient, his family insisted that Mr Hanazono should be sedated immediately as he requested. The doctor and nurse in charge of Mr Hanazono told at the conference that they had learned much from this case. The type of reaction Mr Hanazono's took to his physical deterioration was frequently seen but his family's reaction to the patient was unusual at the PCU.

It seems very difficult for PCU patients to die as they wish to, when it is opposed to the hospice philosophy. This tendency becomes especially evident when patients suffer a severe physical deterioration and thus become physically dependent. In the next section I would like to take up an example of such a patient, who lost her bodily capacities well before her physical death.

1.2. Case study (2) - bodily impairment (Ms Shintani)

Walter (1994: 137) argues that to die one's own way involves two tasks: to assert your right to self-determination, and to accept dependency on carers. According to the hospice philosophy, one should have a good mixture of both in order to die a good death. Either total control or total dependence is not compatible with philosophy of 'good death'.

Here I bring out a case study of a patient named Ms Shintani, who stayed at the PCU for an extraordinarily long time—17 months—until she died in April 2001, although her doctor was not optimistic about her prognosis at the time of her admission. Due to the slow progress of her disease, she lived with her deteriorating body for a longer period than expected.

Ms Shintani was 41 and had breast cancer when she was first admitted to the internal medicine ward at Higashi Sapporo Hospital in August 1999. When her back pain became more severe, she moved to a single room at the PCU within Higashi Sapporo Hospital in November 1999. The prognosis at that time was not optimistic at all—her doctor was expecting that she would have only a few more months to live, which was not told to Ms Shintani.

As she was not married, Ms Shintani's 74-year-old mother from Kitahiroshima city next to Sapporo was attending to her all the time. Throughout her year long stay, I never saw her father at the PCU.

When I first met Ms Shintani at the PCU in November 1999, she was wheelchair-bound. Due to bone metastasis, she had little mobility in her legs. Her legs hurt sometimes, giving her a very unpleasant time, but she said that she enjoyed talking and laughing with me. She also enjoyed painting and playing music with me almost every day.

In January, the condition of her legs suddenly became better as a result of a drip infusion to supply calcium. On 13 January 1999, following the advice of an orthopaedist, she started to practice rehabilitation. She was advised to stamp on the floor and to lift up legs while sitting on the bed. She also ordered a special pair of shoes which fitted the shape of her feet distorted due to the long period of disability. She firstly began to walk while in a wheelchair: she skilfully pushed on the floor with her legs and could move her wheelchair without my support. On 19 January, a catheter tube for urine was removed, respecting her wish. According to the nurse in charge, Ms Miyazaki, Ms Shintani was at that time only thinking about being able to walk again. Until then, she had said she could not think of any future for herself. She had also said that she did not want to undergo any treatment until she became mobile again. For her, without the ability to walk, there was no point in living longer.

On 2 February, she started to walk with a frame. As soon as she could step out of her room on her own feet with a frame, she expressed to me how happy she was. Although she was suffering from severe shoulder ache and leg pain, she said to me, 'I am used to the pain now. It does not bother me at all.' On 28 February, she at last became able to walk without a frame. She walked throughout the PCU corridor using

the railing. According to the patient's record, she was saying 'I want to walk more freely unaided', 'I want to go to the toilet by my own efforts', and 'When the snow melts, I would like to go shopping and to eat at a restaurant.' She even accepted some medical examinations and treatments which she used to reject before, and said 'It is the passage I need to go through [before getting recovered]'. Even the orthopaedist was amazed at Ms Shintani's recovery. I regularly helped her walk, and on 16 March, she could even travel with me to a hospital shop on the ground floor of Higashi Sapporo Hospital. She was certainly looking ahead, and everybody was so impressed with her progress.

On 3 April, I visited her as usual, but I found her lying in the bed and looking depressed. She told me that on the previous day she felt something in her hip joint when she tried to reach something in the refrigerator. Since then, especially her dominant leg (the left leg) had started to hurt. She was also too frightened and worried to try to walk again. Although the orthopedics told her that she could still try to walk with a frame, she was not keen on it, as she could not move her legs as she wanted any more.

On 24 April, she could not stand up from the commode, and had to ask a nurse to lift her up from it. She then completely lost her confidence in getting out of bed, and became very depressed and withdrawn. For example, although Ms Shintani used to enjoy drinking and having some nice food with Ms Miyazaki and me in her room, she never wanted to do so again. Every time I visited her, I tried to offer her some alternative activities, such as going for a walk in a wheelchair, playing a keyboard, and keeping a diary. I also tried to 'revive' her socially by saying that other PCU staff and I would be pleased to help her do whatever she wanted. However, although she sometimes asked me to give her a massage, she never showed any interest in other

activities. The number of times she agreed to my offer to go out of her room decreased as well. Every day she told me that she had no enthusiasm and felt hopeless and despaired. What I could do for her was only massaging her feet without talking. Although I was expecting her to say something to me, she always fell asleep while being massaged.

She used to take care of how she looked very much. Once she persistently complained about her new hairstyle after a hairdresser working for Higashi Sapporo Hospital had cut her hair. A few months later, I heard that she was going to have her hair cut by the same hairdresser. This time, she said to me, 'I don't care how I look any more'. According to her mother, she also stopped putting facial cream on after washing her face, saying that she could not be bothered any more. Similarly, she also gave up carrying out tasks herself: her mother always had to feed her or get things for her. She seemed to have abandoned every effort that she used to make. It was just around this time (June 2004) that Ms Shintani started to say that she wanted to die for the first time. She also said 'No' to the offer from a music therapist who often used to come to her room to play any tunes requested from her. When I asked her if I could bring some videos of her favourite musicians, she said to me that she did not watch anything. Ms Shintani's mother told me that she also said to her that she did not want her sister-in-law (living near Higashi Sapporo Hospital) to visit her any more.

It seemed that Ms Shintani totally gave up herself, and she was totally bed-bound and became static. The PCU staff constantly asked her if she had found something she would like to do, or if she would like to return home for a while, but her answer was always negative.

In July, she started to mumble and to talk to herself all the time. According to her doctor, this was caused by an increase in the amount of calcium in her blood. The

doctor said to me, 'Statistically speaking, it is common to see this kind of symptom approximately one month before death'. He then said to me that Ms Shintani would live only for one more month or so. However, her trajectory of deterioration was significantly slower than her doctor had predicted, and she actually did not die until April the next year.

Ms Shintani's case is remarkable in two respects: firstly, she stayed at the PCU for 17 months, which is significantly longer than the average (45 days); and, secondly, her condition unexpectedly improved shortly after her admission to the PCU. She even became able to walk on her own feet. For her, it is important to have full bodily mobility in order to 'live'. What she kept saying to her doctor was that she did not want to take any aggressive treatments such as radiotherapy or chemotherapy, unless she would become able to move around like when she had been healthy. She also did not want to live if she was to be a burden to her aged mother.

When Ms Shintani lost her capacity for movement from the hip downwards after the temporary recovery, her personality and attitudes towards others changed significantly. She became totally disengaged and withdrawn. She became uninterested in things she used to like, and shortly after this she started to say that she wanted to die soon. When she fell into despair due to bodily impairment, she lost her sense of self. McNamara (2001) argues that:

> [...] the individual person or 'self' is not an entity, separate and independent from his or her biological body. [...] A significantly changed body contributes to a significantly changed self.

> In general, the body is used in many ways to aestheticise the 'interior' self and through the body we express our common bonds with other people. The body, therefore, is instrumental in developing self-identity. When the body begins to break down irretrievably, identity is spoiled (Goffman 1963).
>
> (McNamara 2001: 55)

Ms Shintani's case supports McNamara's argument. As shown earlier, Ms Shintani also failed to rebuild a new self after her bodily breakdown; she lost her self instead, and it never came back to her again. She constantly requested sleeping pills and anti-depression pills so that she could spend most of the time sleeping.

At the same time, she started to become very apathetic. She became disengaged from many things that she used to do and like. She also lost interest in her personal possessions. Lawton (2000) argues that 'personal items and other consumption goods are closely interlinked with the construction and expression of selfhood' (Lawton 2000: 92), offering an example of a female cancer patient who asked nursing staff to put all her personal possessions into a large bag in the cupboard outside the ward, and asked the author to tear up all of the letters, which she used to keep carefully, and throw them away. Ms Shintani never asked me or the nursing staff to destroy what she possessed; however, she started to lose interest in any presents given to her after her condition deteriorated. Nothing given to her to perk her up seemed to be of interest to her.

After she became unable to walk on her own feet, the staff often held special conferences on the case of Ms Shintani. The central concerns were: (1) she did not face her disease; (2) her attitude towards everything was regressing; and (3) she seemed not to have anything worth living for. The PCU staff were hoping that Ms Shintani accepted the reality of her situation and 'lived' more actively with some new

hopes. For example, her psychiatrist once told her to try hard to do her own things, as she was regressing both physically and mentally. However, his advice was too much of a burden for Ms Shintani. At each conference, the staff could not find any solutions to lead her to a good death. Ms Shintani was too dependent on the carers; some staff said that 'it is not Ms Shintani', or 'Ms Shintani has lost her sense of self'. She totally abandoned the idea of taking control over herself and her dying process. Apparently, Ms Shintani did not follow Walter's (1994) criteria for a good death (i.e., in order to die your own way one should assert one's right to self-determination and to accept dependency on carers). Like Mr Hanazono, she too died socially long before her biological death despite carers' efforts.

1.3. Case study (3) - knowledge of the truth (Ms Matsuyama)

Like Ms Shintani, Ms Matuyama, whose case study will be discussed below, also lost hope during her stay at the PCU. Her main problem was that she was too optimistic about her prognosis. When this was corrected by her doctor, she suddenly fell into despair and never regained sense of herself until her last day.

Ms Matsuyama was 66 years old, and had kidney cancer. She was admitted to the PCU on 18 December 1999, although she was from Wakkanai which is approximately five hours away by express train from Sapporo where the PCU is situated. The main reasons for the admission to the PCU were: (1) she wanted to die peacefully at an institution like the PCU; (2) she did not want her neighbours to know that she had cancer; and (3) her daughter who was a nurse working in Australia knew one of the doctors there.

The main concern of her daughter and her doctor was the optimistic prognosis which Ms Matsuyama believed. The patient was thinking that she would live at least for the next few years, but her doctor's prospect was only for a few more months. Especially since her pain was controlled successfully at the PCU[3], Ms Matsuyama believed that she would feel even better soon, and was hoping to go back home to take care of her husband in spring when all the snow had melted away (which was a few months away at that time). Her daughter, however, wanted to send her home as soon as possible, because she might miss the last chance otherwise. According to her daughter, Ms Matsuyama often told her to ask the doctor how much longer she would live.

Her doctor decided to have a meeting with Ms Matsuyama and her daughter in order to correct her optimistic prognosis. During the meeting, she was told that it would be impossible for her to return home in spring, as her condition would worsen much before then. The doctor asked her whether she would like to go back to Wakkanai soon, but her answer was negative. Ms Matsuyama said that her condition at that time was not well enough to play a proper role as a wife at home, and thus there would be no point in her returning home. If she had to stay in bed at home, she would become a burden to her husband, which she hated. During the meeting, despite the shocking news she received, she did not look upset and kept saying 'Fine, fine'.

On 22 January, two days after the meeting, Ms Matsuyama said to a nurse that:

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[3] Although her previous doctor in Wakkanai also administered morphine to Ms Matsuyama, her pain had not been well controlled and she had suffered from half-consciousness, a side effect of morphine.

> I thought going back to Wakkanai was impossible after I talked with my doctor. She said I should go back as soon as possible, as my condition is at its best now, but I don't think I want to. I don't feel that well. [...] I have given up returning home in March. I have no hope, no dream. I don't feel like doing anything at all.
>
> (extract from a medical record)

Despite her strong and composed behaviour at the meeting with her doctor, what the doctor said to her was apparently very shocking and upsetting.

On the following day, Ms Matsuyama reported to a nurse that her legs had given way beneath her suddenly, when she was returning from the toilet in her room. It took her forty minutes to get back to her bed from the toilet. She said:

> I even couldn't crawl back to my bed... I have difficulty in standing up for the toilet now. I think I need to have a catheter soon. I have no dream. I spend the whole day vacantly. I wish I could die soon.
>
> (extract from a medical record)

At a staff conference, a nurse reported that:

> She was very downcast at the news about her prognosis. But we could not help about that, and we really hoped that she would have a new alternative hope or a dream, but she has been so down and her feeling has never come back to the previous level. [...] As a result of modifying the prognosis, she can see the reality, which is good, but her activities of daily living have considerably deteriorated since then.
>
> (extract form a medical record)

Ms Matsuyama also suffered from severe depression, and how to perk her up was the main concern for all the PCU staff. Ms Matsuyama's weakness accelerated within a month, and she died at the PCU while being looked after by her daughter who had rushed to Sapporo from Australia.

In the first two cases, the patient suddenly lost their desire to live when they sensed that there was no curing power in *tairyoku* (Mr Hanazono) and that their condition would lead to irretrievable bodily deterioration (Ms Shintani). It was an internal force and spontaneous feeling, which brought knowledge of imminent death to them. In the case of Ms Matsuyama, however, it was externally transmitted knowledge that stripped the patient's hope to live.

Holding a meeting for a patient to modify the prognosis is not rare at hospices and PCUs. This is because the hospice philosophy emphasizes the importance of patients' knowledge about their diagnosis and prognosis in order to help patients die their own way. A Japanese hospice doctor, Fumio Yamazaki (1995; 1997), stresses that without the patient's knowledge of the truth, there is no way that the patient can decide how to live until he/she dies, and it is also difficult for the medical professionals to understand the patient's real feeling without sharing the information; therefore, informing the patient of their true diagnosis and prognosis is absolutely necessary to practice real hospice care. Yamazaki (1999) demonstrates a case of a male stomach cancer patient in his 70s as a successful example of truth telling. The following is the summary of this story.

The patient was told that he had a stomach ulcer. He was admitted to a hospital where Yamazaki was working at the time in order to undergo an operation, but his cancer was too progressed for surgical removal, so the surgeon had to close the patient's stomach without doing anything. The patient was told, however, that the operation had been successful. Yet, within a couple of weeks after the operation, he started to have the same uncomfortable symptoms as before. As a consequence, he began to distrust the medical professionals and his family. At last, his doctor and family decided to tell him that he had cancer. When he heard the truth, the patient

looked relieved and said, "I knew it was cancer. I wouldn't have this kind of symptom if I had a mere stomach ulcer." He continued, "Now there is no point for me in staying here. I want to return home." Even though he had to be readmitted to the hospital two days before his death, he stayed at home for three months. Yamazaki concludes that:

> If I had not told him the true condition of the disease, he might have lost the chance to return home, and he may have had a lonely death in an inhumane hospital room being suspicious about everything.
>
> Although those around a patient who know the truth, often suggest to him that the patient should go home, if he does not know the truth, he will probably prefer doing so only when he feels better. As a result, most often this kind of patient misses the last chance to return home.
>
> (Yamazaki 1999: 115)

In this manner, Yamazaki explains the importance of practicing truth-telling when conducting real hospice care, which emphasizes the equal relationship between a medical professional and a patient. Lying or keeping secrets is, on the other hand, the expression and indication of a power relationship (Fainzang 2002). Namely, 'holding back knowledge is the protection of one's own place in the social hierarchy' and 'sharing knowledge is sharing power' (Roqueplo 1974, cited in Fainzang 2002: 123). In hospice care, which emphasizes a non-hierarchical team approach, it can be said that sharing knowledge is one of the key principles.

Does truth-telling always lead the best results for both patients and their family? Or is selective information sharing better for them in some cases?

Begley and Blackwood (2000) demonstrate a case which shows that an absolutist approach to truth-telling is sometimes not helpful in a health-care setting. In their example, a male patient suffering from bowel cancer was deliberately not told

the truth in order for him and his wife to make their long term dream—a trip to America with his wife to see their grandchildren for the first time—come true. Although the patient had surgery, his recent test results showed further metastases. This information was, however, decided to be withheld by medical professionals at the request of the patient's wife, who was afraid of the possibility that her husband would get too depressed to carry out his dream after hearing the diagnosis. Without knowing the truth, the patient made their dream come true. The patient had to be re-admitted to hospital for further treatment after the trip. Then his wife told him about his metastases, and she explained why no one had told him the truth. The patient appreciated the kind consideration of his wife and the hospital staff to avoid the potential loss of hope. He said that he would never have gone to America if he had been told the truth. This case highlights that withholding the truth can also help protect and foster a patient's hope and it can be as valuable as truth-telling.

In the case of Ms Matsuyama, however, the truth dashed her optimism and hope for returning home in spring. Should then the truth have been withheld for her? The fact that she was keen to know how long her estimated life was shows that she was intending to return home. Not telling her the truth at that point would have deprived Ms Matsuyama of the possibility to realise this hope. As was the PCU staff's wish, if only she could have fostered an alternative hope, or had decided to return home before spring after being told the truth, she may have been able to 'live' more actively without saying 'I wish I could die soon'.

In the next three sections, we will consider the main problems which prevent the PCU patients from dying as expected by the PCU staff; hopelessness, degradation of self, and social death.

2. Hopelessness

The common feature of the three case studies illustrated above is that each patient totally lost their hope when they became aware of the imminence of death, and at the same time, they abandoned their sense of self. They also 'gave up' and became completely disengaged, withdrawn and apathetic. They did not 'live' as they had been; namely, they died socially a long before the physical termination of life. In this sense, they did not follow the hospice philosophy, and it can be said that they did not die a good death.

Hope has a therapeutic nature. McNamara (2001: 35) notes that 'hope is an important component both in the fight against cancer and in coping with a terminal illness (Perakyla 1991)'. In this regard, encouraging cancer patients to have a realistic hope is the easiest way for PCU staff to guide the patients to a good death, and this is probably the main reason why the staff usually encourage the patients to foster hope. Especially the patients who cannot find a new hope on their own are usually asked whether they want to return home for a few days. This behaviour can be explained as the staff trying to provide hope in anticipation of its therapeutic effect. However, 'hope can be sustained only if the patient continues to have a goal' (WHO Expert Committee on Cancer Pain Relief and Active Supportive Care 1990: 44), therefore, hope should be something feasible, and the overall goal should be 'approached via a series of smaller goals so that the patient and the care-givers are more likely to remain hopeful' (ibid.). Finding hope is, however, not such an easy task for patients with advanced cancer. For them, everything is uncertain due to the unpredictable course of the disease. To make matters worse, the only one certain thing is the imminence of death. Those who cannot find a feasible hope during the dying process become hopeless and live vacantly; this inevitably leads to social death prior to physical death.

3. Degradation of self

Due to the nature of the disease, the condition of all the patients at the PCU worsens every day and often rapidly. The body becomes harder to control, and many patients start to feel that it becomes a different entity. Furthermore, towards the end of life, many patients start to be administered morphine through continuous subcutaneous infusion which makes it less easy to move around. Many also need to be helped even to eat, or to go to the toilet or to use the commode. Under such circumstances, how do patients cope with the immobility and physical deterioration caused by the disease?

In his book, *The Body Silent* (1987), the American anthropologist Robert Murphy describes the progress of his own disease and that of his body deteriorating and becoming immobile. In 1972, the author noticed a small muscle spasm in his back. Within a short time, he learned that this was the early sign of a spinal tumour which over a decade inexorably developed into quadriplegia. Murphy describes how he went through the sense of disembodiment as his condition deteriorated. He explains that:

> It is this "six sense" that allows for co-ordination of movement; without it, talking, walking, even standing, are virtually impossible.
>
> (Murphy 1987: 86)

He also describes how he became rather emotionally detached from his body:

> I have also become rather emotionally detached from my body, often referring to one of my limbs as *the* leg or *the* arm. People who help me on a regular basis have also fallen into this pattern ("I'll hold the arms and you grab the legs"), as if this depersonalization would compensate for what otherwise would be an intolerable violation of my personal space. The paralytic becomes accustomed to being lifted, rolled, pushed, pulled and twisted, and he survives this treatment by putting emotional distance between himself and his body.
>
> (Murphy 1987: 86)

As a result, he said:

> My thoughts and sense of being alive have been driven back into my brain, where I now reside.
>
> (Murphy 1987: 87)

Murphy lost autonomy of his body. His body still physically belonged to him, but not consciously so any more. In order to solve this dilemma, Murphy radically dissociated the mind from the body. He attributes his success in this adaptation to his lack of pride in his body since his young days.

Lawton (2000: 86), however, points out that Murphy could manage the loss of synchrony between mind and body because he was able to retain a viable sense of self. She further points out that Murphy experienced to some extent a redefinition of self even after his bodily deterioration had become very severe. This kind of self redefinition or 'the redemptive shifting of emphasis from the body to the mind' (Thomas Couser 1997: 185, cited in Lawton 2000: 86) observed in autobiographical and auto-ethnographical accounts of illness and disability, like Murphy's, may be somewhat unusual. Lawton (2000) further explains that this is because 'those who undertake autobiography tend to be intellectuals, whose major sources of self-esteem—and income—are less likely to be damaged by physical disability'

(Thomas Couser 1997: 205, cited in Lawton 2000: 86). In most cases, however, 'illness and disability may turn people so far inward that they become virtual black holes' (Thomas Couser 1997: 5, cited in Lawton 2000: 86), and 'can annihilate selfhood' (ibid), rather than encourage patients to rebuild a new self. Additionally, as Lawton describes, those who receive hospice care in their final stage of their illness experience a very rapid physical deterioration, and thus they have no time, 'or a context, in which to mask and/or reconfigure their bodily deterioration, and thereby "remake" a self' (Lawton 2000: 87), unlike those who are at an earlier stage of their illness or those with long-term disabilities and chronic conditions. In fact, during my fieldwork I observed that an eighty-nine year old patient with prostate gland cancer said:

> My legs don't work any more, so I can't even go to the toilet alone. I'm feeling so sad... I have to be taken care of by others. I know it is normal to be looked after to some extent anyway, as I am old, but this has happened to me *so suddenly*.... So, I have no time to get used to it [the change]....
>
> (emphasis added)

This comment supports Lawton's argument that a rapid physical deterioration confuses patients, and makes it difficult for them to retain their sense of self. An unexpected and sudden decline in physical ability may also make patients think that they have become totally immobile and useless.

Similarly, one of the aforementioned patients, Ms Shintani, said the following to her doctor when the bone metastasis started to develop:

> I feel as if I were totally disabled. [...] I also feel as if I were a weak person who can't do anything, or a complete subnormal. I feel horrible.

Due to the bone metastasis, she suddenly lost most of the capacity for movement of her legs, and seemed totally to have lost interest in living her life, In fact, she was actually still able to perform most of her daily activities at that time, and the doctor was suggesting that she should try some treatment at least to delay her cancer development and prolong her life. For Ms Shintani, however, losing the ability to walk meant the end of her life, instead of merely one of the symptoms she would have to go through before dying. She was, therefore, not interested in undergoing any kind of treatments to delay the development of the cancer, nor in prolonging her life. She was, in other words, waiting for death. Her case illustrates how disabilities 'turn people so far inward that they become virtual black holes' (Thomas Couser 1997: 5, cited in Lawton 2000: 86), and 'can annihilate selfhood' (ibid), rather than encourage people to rebuild a new self in cases of cancer patients who mostly experience sudden and rapid physical deteriorations.

Another reason why those who receive care at a PCU or hospice in their final stage of life have difficulty in rebuilding a new self is the fact that most patients go into remission as a result of successful pain and symptom control soon after their admission to the PCU. Consequently, some start to think that they will not have to suffer from any pain and symptom until their final day, and others even start to believe that they may be able to recover from the cancer (see chapter 5). In this case, when pain returns due to the progress of illness, patients feel that the deterioration has happened even more rapidly and the loss of self becomes even more devastating. Moreover, I observed one female patient with stomach cancer who seemed to believe that she would be able to live not only without pain but also without becoming bed-bound until her final hour as a result of successful pain control. She said:

> I appreciate the fact my pain has been well relieved, but if I become unable to move, I will have a grudge against this place [the PCU][4].

The primary reason for the admission of this patient to the PCU was pain control. As she had not been able to receive satisfying pain control at her previous hospital, she moved to the PCU at Higashi Sapporo Hospital with a thread of hope. As a result her internment, her pain was well managed. Mainly due to this fact, she may have started to think that she would not suffer from any deterioration at all until her final day. When her condition became worse and the pain was not as successfully managed as before, she started to complain that there was no point in her staying, and she left the PCU for elsewhere. It can be said that the problem she had was not only pain but also the fact that she could not face her unexpected physical deterioration. For those who enjoyed remittance like this patient, any deterioration could be unexpected, and hard to accept. Sudden physical deterioration can be too shocking for patients to be able to rebuild a new self afterwards.

What happens next to those who fail in rebuilding a new self? According to my observation, it seems that they become withdrawn and disengaged from their surroundings. I observed that many patients go through this experience and become 'non-persons' prior to their physical cessation. They finally become disengaged from all the events and relationships taking place around them, which results in their social death.

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[4] The doctor who heard this said the following at a staff case conference: 'She always says "I don't mind dying", but she ignores the fact that she will inevitably go through physical deterioration before dying.'

4. Social death

In his book *Passing On: the Social Organisation of Dying,* the American ethnomethodologist Sudnow (1967) explored death and dying within the modern hospital context in the United States. His work describes the medical management of death and dying. The picture he paints is one of death hidden and obscured by staff pretences, and an environment where the value of organizational efficiency is given more weight than that of human dignity (Hart *et al.* 1998: 67). Sudnow (1967: 74) suggests that in the modern hospital context death can be divided into three categories: clinical death (the appearance of 'death signs'), biological death (the cessation of cellular activity) and social death. He sees 'social death' as death which, within the hospital setting, 'is marked by that point at which socially relevant attributes of the patients begin permanently to cease to be operative as conditions for treating him, and when he is, essentially, regarded as already dead' (ibid.). Although perhaps still 'clinically' and 'biologically' alive, the patient is possibly treated as dead at the point of social death and given what Sudnow calls 'nonperson treatment' (1967: 75) such as commencing funeral arrangements, or planning an autopsy.

Similarly, McNamara (2001) and Lawton (2000) discuss social death within a 'hospice' setting. McNamara points out that 'the patient's inability to care for themselves signals the relinquishing of control and the beginning of social death' (2001: 57). She further notes that social death happens 'when the terminally ill person ceases to interact with others in a socially meaningful way' (ibid.). Lawton's point of view is very close to McNamara's. She indicates that patients enter the state of social death when their sense of person/self is lost and they cease to have involvement with others.

As I discussed in chapter 5, at admission to the PCU patients lose the social identity they possessed when they were healthy. However, I observed hardly any patients who fell into social death immediately after admission. Although most of the patients seemed to lose their social identity to some extent, a number of patients even became more cheerful due to the successful pain control, and some were pleased with the quieter PCU environment and more careful nursing they received. Neither did I observe any cases of carers who started to practice 'nonperson treatment' on the patients.

The reason why this is the case is probably due to the nature of PCUs, where the patients are encouraged to sustain their self until their last day, and carers also understand and support this idea. This kind of attitude, i.e., to suspend the actual occurrence of social death, is probably a new concept both historically and geographically. As shown in chapter 2, once an individual's imminent death is recognized, those who are around usually treat him or her as a nonperson immediately and often try to bring physical death forward by encouraging him or her to die physically. Sudnow (1967) also illustrates how the hospital staff give nonperson treatment to the socially dead. The hospice philosophy was, however, established and is practiced in order to reduce the chance that patients die socially before their physical death, and even if the patients die socially they are never treated as a nonperson. One aspect of palliative care can be described as a struggle between the patients, whose sense of self is gradually deteriorated as the disease develops, and the carers who wish the patients to sustain their self until the last day.

Within a context of palliative care, social death should not occur; or if it does occur, it should happen as close to physical death as possible. In reality, however, I

observed that the majority of patients experienced the loss of self which led to social death before they physically expired.

5. Good and bad death

None of the deaths described in the case studies in this chapter were considered as good deaths by the PCU staff. This is probably because the patients went through a distressing period for a long time between social and biological death. Becoming 'not like him/herself' is against the hospice philosophy, so it should have been avoided. In this sense, social death is a bad death within a context of palliative care.

It is very upsetting and distressing for both the family and the PCU staff to see patients becoming withdrawn[5]. During my fieldwork, I also frequently observed some families saying that they did not know what to do and what to say to the patient who became too weakened to maintain him/herself as seen before. I also heard other families say that they were so vexed to see patients becoming non-persons.

Families blamed themselves for being useless and helpless at the most important moment for the patient. Although the WHO Expert Committee on Cancer Pain Relief and Active Supportive Care (1990: 44) refers to the importance of the role of health care workers at this stage, and asserts that they should not feel powerless in the face of death, the PCU staff also seemed to become confused and not to be able to find the best way to support those who died socially. Social death disturbs the

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[5] One of Mr Hanazono's daughters' remark that 'my memory of my father is only how I remember him when he was healthy. I do not want to remember anything about him after the admission to the PCU', manifests the upsetting feeling that the carers have.

dynamic at the PCU; it confuses the cooperative spirit which PCU staff and family members have in order to help patients live as themselves until the last day.

If dying socially long before physical death is considered bad, the reverse should be considered good. Namely, if a patient accepts death calmly and lives as actively as possible until his or her final day, as the hospice philosophy advocates, his or her death would be considered good.

During my fieldwork at the PCU, I encountered only two cases which were described as a good death by the staff[6]. One is one of my informants, Ms Yasukawa (aged 36, uterine cancer patient), and the other one is Ms Yamada (aged 73, stomach cancer patient).

Ms Yasukawa 'lived' as herself until the last day. As she was a young mother of a small boy who was five years old at that time, she still had many things she wanted to do for her son, thus she tried to complete her unfinished tasks until a few days before her death. She also made a great effort to look happy all the time for the sake of her family. All the above facts made her death look even sadder and dramatic. The way she died moved many staff at the PCU. I remember that the doctor in charge was crying at the nurses' station after Ms Yasukawa's death, saying, 'I encounter such a death once in a while. I am so impressed by her attitude. She really did her best.'

Just like Ms Yasukawa, Ms Yamada was also fully aware of her diagnosis when she entered the PCU. She said to her doctor that she would like to make her life come to an end nicely. The doctor was very impressed with her attitude and told me that she had accepted her death squarely. Ms Yamada was very keen to discuss pain control with her doctor and to go back home as often as possible. She was also very

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[6] The reason why I was aware of only two cases of good death at the PCU is probably not only because fewer patients died a good death but also because the staff were more likely to discuss difficult patients. Patients who are dying well did not come up to the staff's conversation unless their dying process was remarkably impressive to the staff.

polite to all the staff and never complained. She wrote her will and sorted out her belongings well before her death. She also talked with her son to her heart's content. Her doctor told me later that she had died very quietly and peacefully.

These two patients did not die socially before they physically died. They both 'lived' actively until their last day. No one can tell that whether Ms Yasukawa and Ms Yamada thought they were dying a good death, but their death was both regarded as good by the PCU staff. The concept of good death within the context of palliative care will be further discussed in the next chapter. This will help us understand why this particular way to die is considered good in palliative care and how patients are treated to help them die a good death.

6. Summary

In this chapter, I have described the reality of palliative care using the case studies, and also discussed 'obstacles' to practicing the hospice philosophy.

In order for patients to die a good death, social death should if at all possible be avoided at PCUs, or at least social death and physical death should coincide or occur as closely as possible. If patients die socially and biologically at the same time, it is thought that they did not undergo a severe distressing period, which helps the patient die a good death, and also reduces the level of stress carers would otherwise experience.

The most important function of PCUs is, therefore, to slow down or possibly stop the progress of social death until biological death: 'good hospice care pushes back social death until the moment of physical death' (Walter 1994: 51). Social death can also coincide with biological death when heavy sedatives are administered to the

patient. In this case, however, quasi-physical death is brought forward by medicine. These two attitudes—one pushing back social death by care, and the other bringing physical death forward by medicine—seem to display totally different attitudes toward death, but in fact they both share the same idea that social death and physical death should occur as closely as possible. Since both extremes share the same aim, it is normal that the easier one is practiced more often than the other one. In a PCU environment, however, which one really is the easier to practice in terms of staff and PCU organization?

Within the context of van Gennep's rites of passage, the dying process is regarded as a transitional period between the admission to and discharge from a PCU. Especially when patients started to die socially or when they are in the state of social death, they are considered either not alive (not him/herself any more) or dead, and hence they are indefinable and unclear transitional-beings or 'liminal *personae*' (see chapter 2). Those who are transitional-beings or 'liminal *personae*' are normally seen particularly polluting and dangerous. In the case of PCU patients, the facts that they are not him/herself any more and that it is difficult to predict what is going to happen to them even in the near future increase the amount of carers' dreadful feelings towards the patients.

Although the hospice philosophy encourages both the dying and their family to accept death as part of the natural process, my fieldwork observations highlight that it is not easy to do so for either of them. As transitional-beings or 'liminal *personae*', PCU patients become objects of a fear and dread to carers rather than those who they wish to live with as positively as possible until the last minute.

As seen in chapter 3, at traditional funeral rites, a number of rituals are conducted during this transitional period in order to remove the fear and dread caused

by uncertainty and to send the dead's soul to the next world as smoothly as possible. Is anything equivalent to this kind seen during the dying process at PCUs? In other words, are there any 'rituals' conducted in order to decrease the carers' fear towards the dying and in order for the dying to die as smoothly as possible? Does the hospice philosophy which aims at achieving a good death help both the carers and the dying in this sense?

In the next chapter, I would like to further consider this problem—what is actually practiced during the dying process at PCUs, and the role of the concept of good death during this period.

Chapter 7: Making Death Good

In the previous chapter we looked at the dying process of the PCU patients and demonstrated what kind of death is considered good and bad at the PCU. We also examined factors which hinder the practice of hospice philosophy. The difficulty in achieving a good death and the gap between theory and practice were highlighted as well. In this chapter we investigate how the PCU staff attempt to close this gap in reality. We focus on treatment given to patients, medical practice, and routine procedures conducted at the PCU, and examine their meanings within the context of the transitional period in order to further consider how van Gennep's theory of rites of passage applies to the dying process at PCUs.

In the next section, I investigate what kind of death is considered good in the context of palliative care both in the West and in Japan, which helps to understand how filling the gap between theory and practice is attempted in reality. This will be followed by an analysis of how a good death is made possible at the PCU. I examine the ritualistic aspects of routine and treatment based on my fieldwork observation, and look into how routines and treatment function for the PCU staff and the patient in order to achieve their common aim (i.e., a good death). Lastly, I will briefly mention the routines taking place at the end of the patient's life, considering this as the stage of incorporation.

1. Death and the hospice philosophy

The modern view of death is expressed in the aims of the hospice movement, which began in the 1960s in the United Kingdom, and which encourages patients and their family to affirm life and to regard dying as a normal process. At the same time, its philosophy offers a support system to help patients live as actively as possible and to sustain their selfhood until death. It also stresses the importance of respecting patients' autonomous attitudes. Here, patients and family are supposed to accept death, but unlike the situation in many traditional societies, they are not supposed to be treated as already dead.

The dying process advocated by hospice philosophy is not only different from that illustrated in studies of other societies, but also it includes some contradictions within itself as I highlighted in the previous chapter. Most cancer patients will experience physical degradation of their body towards the terminal stage of life, and will become more dependent on carers and others. This means that it is impossible for patients to regard themselves as able to retain their sense of autonomous decision-making. Additionally, I observed that many patients abandon their social roles as soon as they enter the PCU, and lose part of their previous sense of selfhood and agency. The progress of illness thereafter is often too rapid for them to be able to develop a new sense of selfhood more in tune with their new circumstances. This also means that patients neither live actively nor maintain full selfhood during the period between admission and their death. I observed that many patients then become totally withdrawn and switched off, which results in social death long before biological death, as shown in chapter 6. This kind of death is not referred to as a good death at the PCU, because it goes against the hospice philosophy.

Now I would like to further explore how the PCU staff deal with the inevitable contradictions between the hospice ideology of a good death and a reality where death can sometimes be far from good, and how the staff and the patients try to pursue a good death in this environment.

1.1. Good death in Western healthcare settings

As discussed in chapter 2, from the anthropological point of view, death which promises a rebirth for the individual and also a renewal of the world for the living is considered as a good death. Therefore, death which disturbs the continuity of the society, such as accidental or premature death, should be avoided. Additionally, as the influence of bad death on the society is larger than that of good or normal death, bad death is more distinctly acknowledged than other types of death. This is in contrast to the tendency in contemporary society, especially where the hospice culture is disseminated. The hospice philosophy explicitly represents aims to help patients achieve a good death. This is probably because in modern societies, a bad death does not have such an immense influence as in traditional societies.

What kind of death is seen as desirable and good in the realm of hospice culture? The notion of a 'good death' sounds paradoxical within the context of western medicine. Death is generally considered as a defeat of medicine, so ageing, disease, and death are inevitably regarded as 'bad'. On the other hand, being young and healthy is admired as good and beautiful. In this situation, how can people die a good death?

A number of discussions on this issue have been carried out from the professional perspective, and have appeared in well-known Western medical journals. Let us look at some definitions of a good death as given in this context.

In *The Lancet*, Emanuel and Emanuel (1998: 22) present the following definition of a good death as held by the Institute of Medicine in the United States:

> A decent or good death is one that is: free from avoidable distress and suffering for patients, families, and caregivers; in general accord with patient's and families' wishes; and reasonably consistent with clinical, cultural, and ethical standards.
>
> (Emanuel and Emanuel 1998: 22)

The editor of *The British Medical Journal*, Richard Smith (2000), extracts twelve principles of a good death identified by the authors of the final report on 'The Future of Health and Care of Older People'. These are:

- to know when death is coming, and to understand what can be expected
- to be able to retain control of what happens
- to be afforded dignity and privacy
- to have control over pain relief and other symptom control
- to have choice and control over where death occurs (at home or elsewhere)
- to have access to information and expertise of whatever kind is necessary
- to have access to any spiritual or emotional support required
- to have access to hospice care in any location, not only in hospital
- to have control over who is present and who shares the end
- to be able to issue advance directives which ensure wishes are respected
- to have time to say goodbye, and control over other aspects of timing
- to be able to leave when it is time to go, and not to have life prolonged pointlessly

(Smith 2000: 129)

The medical sociologist David Clark (2002) lists elements of a 'good death' in modern Western culture in his article for *The British Medical Journal*. These include:

- pain-free death
- open acknowledgement of the imminence of death
- death at home, surrounded by family and friends
- an 'aware' death—in which personal conflicts and unfinished business are resolved
- death as personal growth
- death according to personal preference and in a manner that resonates with the person's individuality

(Clark 2002: 907)

In *Cancer Practice*, Lynch and Abrahm (2002: 33) cite Byock (1997) to describe the process of 'dying well' as follows: 'the amelioration of physical, psychosocial, and spiritual distress, the exploration of the meaning and purpose of one's life and death, and the delineation of personal legacies in the weeks and months preceding death'.

Looking at each of these definitions of a good death, it is apparent that within the context of Western medicine the notion is associated more with the personal domain than with society. An emphasis on the continuity of society or on the regeneration of life is scarcely seen; instead, the patient's awareness, autonomy, ability to control external events as well as him/herself, right to have dignity and privacy, and to share the end with his/her family are highly valued in contemporary Western societies. However, it seems that the contingency of death should still be avoided as seen in more traditional cultures. For example, the principles of good death cited in Smith (2000) above (i.e., to have time to say goodbye and control over other aspects of timing, and to be able to leave when it is time to go, and not to have life

prolonged pointlessly) indicates that it is not desirable to die without good control over the contingency of the biological occurrence.

Hospice philosophy encourages us to be aware that death is something that happens to us all, and is part of the natural process of life. Yet, in order to make this natural occurrence good and acceptable, there are many duties for patients to complete before dying. The passage to a good death can be very long and steep from the patient's perspective.

The American medical anthropologist Arthur Kleinman (1988) gives an example of a good death of a thirty-three-year-old writer, Gordon Stuart, who had cancer. Gordon was aware of his imminent death. He established a good relationship with his doctor, Hadley Eliot, and had open discussions with him about his condition and death. Gordon knew how he wanted to die; dying while surrounded by his family, his favourite books and music at home. He tried to put his affairs in order before his death. After Gordon's death, Hadley reflected upon events as follows:

> Gordon died a good death. He was clear right up to end. He had fortitude and character and died as he lived, very much his own person. He was no less angry, not accepting at the end, but he kept his sense of irony, his way with words, he seemed to grow into whom he wanted to be. His death confirmed his life.
>
> (Kleinman 1988: 149)

Gordon's death was good, and it was highly respected by his doctor. It exactly followed the model of a good death from the professional perspectives discussed above. However, Kleinman (1988) is skeptical about the universality of the notion of good death, as some people, for instance, would be frightened or otherwise repelled by Gordon's self-imposed demand that he be fully conscious of his end. It is natural to say that the notion of good death differs from one person to the other. Kleinman

(1988) points to the work of culture which has a powerful impact on the attitude towards death and dying. Additionally, lay people's attitudes towards a good death may differ from those of the healthcare professionals who look after the dying everyday.

Payne *et al.* (1996), who conducted research in a palliative care unit in the south of England, demonstrate how patients and health professionals differ in their conceptualisations of a good death. Patients describe good death in terms of dying in one's sleep, dying quietly, and dying with dignity. Many also wish for a sudden death, which is not often emphasised by palliative staff. In practice, a sudden or unexpected death causes stress among hospice staff (McNamara *et al.* 1995), because the patient dies without preparing for it—which is against the hospice philosophy. Similar attitudes are observed in Japan. As discussed in chapter 4, a quick death without being bedridden (*pokkuri*) is also one of the highly desired ways of dying for lay Japanese people; however, PCU staff do not consider this a good death, since they expect patients to sustain their self and to 'live' until the final hour.

1.2. Who wants good death?

As we have seen, dying well is not merely a matter of the patient who is dying: in practice, it involves the carers and the healthcare system established within an institution. In fact, as well as being of concern to the dying patient, the notion of good death 'benefits palliative care administrative structures by supporting their philosophies and goals and by facilitating the smooth running of the organisations' (McNamara 2001: 47). In other words, failure to achieve a good death results in a traumatic experience for patients and their families, and causes problems in upholding the philosophy of the PCU as an institution (McNamara 2001: 47). Bad deaths often

physically and emotionally exhaust the healthcare staff, and they also drain resources, as greater time is spent in care and discussion amongst the staff.

My experience at the PCU at Higashi Sapporo Hospital supports the argument above. Considerable time was spent on 'difficult' patients such as Mr Hanazono, Ms Shintani, and Ms Matsuyama shown in chapter 6. The PCU staff in charge of these patients were very exhausted physically and emotionally. Staff conferences were held very often in order to 'straighten out' the dying process of these patients. Even after their death, staff conferences were held to reflect what could have been done to ensure a better outcome. On the contrary, patients dying a good death (such as Ms Yasukawa and Ms Yamada) seemed to save the PCU staff trouble. Staff conferences to discuss this kind of patients were rarely held. Those who did not cause much 'trouble' were called 'good patients'.

Throughout my stay at the PCU, I could not help feeling that there were implicit 'rules' for a good death, and whether or not a patient followed these 'rules' decided whether he or she was a good patient or not. In other words, there seemed to be institutional definitions of 'a good death' and 'good patients'. Those who do not drain staff's emotion and time and the PCU's resources are considered to contribute to the smooth running of the PCU, and thus regarded as good patients, and their death is categorized as a good death. Why has this been the case recently in the hospice and palliative care setting? Many Western scholars attribute such an attitude to the routinization and medicalization of hospice.

James and Field (1992), for example, examine the development of the hospice movement using the sociologist Max Weber's concept of charisma. They demonstrate how Weber's framework might be applied to the hospice movement. In Weber's view, 'charisma' is an agency which produces radical innovation in institutions and

established beliefs (James and Field 1992: 1365). James and Field further summarize the main features of charisma as follows:

> (1) Charismatic leadership is one which has no organized 'machine' at its disposal and whose power has not been gained through institutional procedure (Andreski 1984).
>
> (2) It is a uniquely personal response to crisis and 'inhuman' experience (Bendix 1966).
>
> (3) Essentially creative and disruptive, it promotes a new 'value orientation' that inevitably collides with the existing one (Burbaker 1984).
>
> (4) The charismatic leader who seeks to acquire possessions receives them in the form of donations, endowments or contributions (Bendix 1966), themselves uncontrollable, irregular sources of income.
>
> (James and Field 1992: 1365)

James and Field then point out that all of these features can be seen in the early development of the hospice movement and particularly in the person of Cicely Saunders (a founder of this movement as noted in chapter 1). According to Weber, however, 'leadership can remain charismatic only so long as the number of followers is small', and 'when exposed to everyday demands charismatic movements inevitably become confronted with the need to create an administrative machine; the acquisition of funds; and the problems of successions—and so the process of routinization begins' (James and Field 1992: 1365). In order to survive, charismatic movements need to increase their followers, which inevitably routinize the idea or philosophy established by the charisma leader. In the case of the British hospice movement, the early hospice, which was developed outside the healthcare mainstream, resonated with wider public concern about the care of the dying. As the hospice philosophy spread, its initial development as a separatist organization gained support on a

national level, which resulted in the dissemination and legitimation of its principles. The assistance of national voluntary organizations has played a key role in terms of sponsorship for the movement. The hospice movement, then, has been re-absorbed into the mainstream of British health care services, 'as an exemplar of good practice in terminal care, and an influential player in policy making' (James and Field 1992: 1368). Routinization of the original idea of the hospice care has inevitably occurred because of the need for more followers and the movement's need for stability.

When routinization occurs, bureaucratization comes next. The early hospices were progressive: there were no rules to follow, no established authorities or organizations to set standards. However, with the increase in the number of followers, hospices needed to be standardized at the national level. In order to meet the national standard, professionalization of healthcare workers has become important for more credible and efficient care. Seeking credibility in hospice care has also made it more rule-bound. Additionally, in order to justify the funding of hospice care, audits will be required by the central government and local health authorities, which standardizes the quality of hospice care in terms of cost-effectiveness, so that the emphasis shifts away from the quality of patients' remaining life, autonomy, and informed choice of treatment.

McNamara *et al.* (1994), who carried out a study of hospices in Australia, demonstrate the institutionalization of the good death within the hospice setting, and the tension that arises between the maintenance of the good death ideal and the maintenance of the organization. As noted earlier, once hospice care has been re-absorbed into the mainstream of the healthcare system, hospice and palliative care ought to function within organizations. Under such a system the concept of good death changes to what is beneficial not only to the dying but also to the organizations

that maintain the service (McNamara *et al.* 1994). 'The healthcare professional staff, therefore, while supporting the principle of patient autonomy central to the good death experience, may find that patient compliance makes their jobs easier and more efficient' (McNamara *at al* 1994: 1506). Payne *et al.* (1996: 308) also indicate that good death plans may serve a function for healthcare staff rather than patients, as the staff feel less stressful if the patient accepts that they are going to die.

The above discussion of the Western hospice environment has demonstrated that the hospice movement, which was developed as a charismatic movement, has inevitably followed a trajectory towards medicalization, institutionalization, and routinization. As a result, the concept of a good death functions to maintain the organizational stability of the hospice or palliative care unit, and this consequently constrains the patients' dying patterns. The notion of good death, originally established for the benefit of the dying individuals, has become more institution-centred, along with the medicalization, institutionalization, and routinization of hospice care. Good death, therefore, is required not only for the lives of the terminally ill and their families, but also for the satisfaction of the staff and for the organisational maintenance of PCUs. Therefore, one might say that an emphasis on good death correlates with the increased medicalization, institutionalization, and routinization of hospice care. The more stress is laid upon the ideal of a good death, the more hospice care becomes institutionalized.

1.3. Good death in Japanese healthcare settings

Now let us turn our eyes to the Japanese situation. In this section, I examine the concept of good death currently spread within the context of the hospice culture in

Japan by analysing some case studies reported from Japanese healthcare professionals.

Japanese nurses Hirano *et al.* (1995) report a desirable death [1] they encountered at their hospital. They highlight the case of a seventy-nine year old woman with malignant lymphoma who died 'as she wished to'. Her death is described as follows:

> She died in the way she wished to. She made her farewells to all the people she wanted to see before dying. She did not have regret or agony, as it was described in her words, 'I have nothing to regret. I want to go to the next world soon.' Her death was, therefore, the death that she chose, and she desired. Additionally, her death was not merely the termination of her life, but also a kind of a death education to her surroundings. In this sense, her death was a desirable one not only for herself, but also for those who were important to her. It was also a complete death.
>
> (Hirano *et al.* 1995: 55)

Hirano *et al.* go on to discuss what makes a 'desirable death' based on this case.

> (1) The patient knows that her disease is lethal, and accepts her death without any dreadful feeling toward death and the afterlife. (2) There is a family who respect and support the patient's wish, and the healthcare staff understand her wish very well. (3) A good relationship between patient, family and the staff is established, which helps to remove anxiety of the patient and the family. (4) Good symptom control is conducted.
>
> (ibid.)

A medical doctor, Gōchi (1995: 141), said that he tries to carry out the palliative care which will make the patient think 'I am happy to be here to spend the

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[1] The term, 'good death (*yoi shi*)', is hardly used in Japanese literature. Instead 'desirable death (*nozomahii shi*)', 'peaceful death (*yasuraka na shi*)', and 'beautiful death (*utsukushii shi*)' are used to describe a good death.

rest of my life'. He argues that there are seven problems for health professionals attempting to realize a peaceful death for their patients. They are: (1) the basic medical management of body and basic physical care; (2) good symptom control and good care of the patient; (3) humane team care; (4) good maintenance of the environment where the patient lives; (5) care for the family and coordination of a good relationship between the patient and the family; (6) providing necessary information and helping the patient carry out what he wants to achieve; and (7) leaving the patient's fate to himself.

A nurse from the National Cancer Centre, Maruyama (1995: 145), argues that in order to die a peaceful death, a patient should; (1) be relieved from physical pain; (2) be in a mentally stable state; and (3) be able to realize her wish. Maruyama emphasizes the importance of good communication between the patient, the family, and the healthcare staff, because the patient will suffer from suspicion, anxiety, and isolation otherwise.

What makes a death good (or peaceful and desirable) within the context of the Japanese healthcare setting can be summarized as follows: (1) good symptom control; (2) good relationship between the patient, the family, and the staff; (3) good support to help the patient achieve something that remains undone; (4) calm acceptance of death; and (5) provision of help for patients to accomplish unfinished tasks. The definition of a good death in Japan is, in many ways, very similar to its Western counterpart—both place an emphasis on pain relief, accomplishing uncompleted tasks, and being aware of death[2]. This enables patients to live as themselves until the end.

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[2] Unlike the Western definition, however, Japanese healthcare workers stress the importance of a good relationship between staff and patients.

1.4. Palliative care units – a place for a good death?

PCUs are originally designed to help patients die a good and peaceful death. However, not all PCU patients follow its guiding principle. In the words of a hospice doctor (cited in the TV and radio writer Rokusuke Ei's book '*Daiōjō* (A Peaceful Death')):

> I want my patients to die as they wish to. As a hospice doctor, I think this way, but many patients do not have any ideas about their way to die. Thinking only about how to live does not mean much at the end of life.
>
> (Ei 1995: 70)

This doctor seems to imply that patients receiving hospice care should clearly accept their death and be ready to die. Is hospice care only for those who know how to die?

The hospice doctor Yamazaki, holds a similar view. He emphasizes that hospice care should be practiced anywhere regardless of whether or not there is a hospice facility (i.e., one that meets governmental standards) (2000). Yamazaki, however, defines the features of hospice care as follows:

> Hospice can mean both a care programme and a facility where symptom control and care are mainly conducted, and where the staff help those who wish to live as comfortably as possible until the very last day based on their own accord and choice, and consequently wish to die a peaceful and natural death with dignity.
>
> I think that hospice care is the practice of the hospice programme which supports the life of *this kind of patient.*
>
> (Yamazaki 1995: 104-105, emphasis added)

Yamazaki especially puts a strong emphasis on the patients' knowledge of hospice care and its philosophy as well as their true diagnosis; the patients themselves

should choose to enter the hospice/PCU on their own will (1996b; 1997). This is because it is impossible for the staff to practice hospice care if the patients do not know their true diagnosis and, consequently, do not know how they want to live until the last day. Yamazaki (1995) continues that:

> If hospices or PCUs accept any terminal cancer patients, those patients [who are not aware of their true diagnosis and the hospice philosophy] may only weaken in the course of time without expressing their own will until they die. For those patients, a hospice will be *a mere place to die.*
>
> (Yamazaki 1995: 105, emphasis added)

Yamazaki's idea may imply that there should be strict admission criteria for hospices/PCUs to admit patients, and only those who meet the criteria should be allowed to enter care[3]. This maximises the chances of patients being able to die a good death, contribute to maintaining the hospice philosophy, and lessen the emotional and physical exhaustion of the staff. It also saves resources and time in care and discussion amongst staff. Initial selection of the patients at admission reduces future burden to the staff and facilitates the organizational maintenance of PCUs. The hospice philosophy was originally established for the welfare of humanity, based on a charitable motive. However, the above quotations seem to show that there is an elitist tendency amongst contemporary hospices and PCUs in Japan.

1.5. Dying process as an transitional period

Dying a good death involves not only the dying individuals, but also the carers and the healthcare system established within an institution. Especially due to the medicalization, institutionalization, and routinization of hospice care, the concept of a

good death functions to maintain the organizational stability of the hospice or palliative care unit, and lessens the emotional and physical stress of the staff. The good death ideology has become 'a subtle form of surveillance of dying' (Clark 2002: 906), and consequently constrains the patients' dying patterns in contradiction to the ideology.

As discussed in chapter 4, 'dying naturally' seems to be generally considered a good death in contemporary Japan. During my fieldwork, however, this concept was not found very important by the PCU staff. For example, when Ms Yasukawa (see chapter 6) had trouble with bowel movement, her doctor suggested that she undergo an operation to have a stoma, although she was at that time already at the terminal stage of her life and she wanted to go naturally until the last day. This opposition arose possibly because a natural death is associated with little medical intervention; moreover, even if natural death would occur medical professionals would not feel a great sense of achievement in working toward a natural death. Natural death is not good enough for those medical professionals who pursue the letter of the hospice philosophy.

One might say that one of the ways to maximize the chances of patients being able to die a good death (within the context of hospice philosophy) is to carefully select the patients at admission. This is because it helps the staff have 'committed' patients to start with who will contribute to smooth running of the PCU[4] (see also Yamazaki 1995).

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[3] Yamazaki is not only a head doctor at the hospice where he works, but also one of the influential leading hospice doctors in Japan. Therefore, his argument cannot easily be ignored.

[4] In the case of the PCU at Higashi Sapporo Hospital, the most important 'admission criterion' was the patient's giving up receiving any curative treatments. This was because the patient would otherwise become unsatisfied with the PCU, and this would disturb the smooth running of the unit.

This kind of view strengthens the idea that the patient's dying process is an transitional or liminal period. Only those patients with an appropriate shared aim (i.e., to die a good death) enter the PCU. At their admission, the patients abandon their social identity which they used to live by when healthy. They then enter what Turner calls *communitas*, which is characterized by homogeneity and comradeship of those who enter the new environment. The staff are there to guide them to a good death, and in order to do so, various treatments and care are given to the patients who share this aim. The patients stay at the PCU most of their time until they die physically and their body returns home in the end just prior to their funeral.

In the next section, based on my fieldwork experience, I analyze the shared meaning of medical routines, treatment, and practice conducted by the PCU staff, and how they are implemented to generate a good death within the PCU.

2. Managing the patients

The PCU staff use a variety of means in order to encourage the patients to maintain their sense of self and 'live' as themselves until the last day of their life. Such means are simply taken as routine in practice. Yet, these routines can be regarded as rituals to remove dreadful feelings towards death and dying during the transitional period (the dying process) and possibly to make death 'good'. Here I would like to analyze how the concept of ritual can explain the routines conducted by the PCU staff.

2.1. Characteristics of ritual

What is ritual? Can medical routines be defined as 'ritual' from the anthropological point of view?

Many anthropologists have analyzed the function of ritual and attempted to define it; yet, no generally accepted definition of ritual exists. Watson (1988: 4), however, points out that ritual is commonly perceived as something associated with transformation, especially transformation of one being or state into another, and this transformative aspect sets ritual apart from other social actions.

Structural functionalists view ritual as a tool to maintain social coherence, and to reinforce certain values for the smooth running of society. Others are skeptical about this idea, and argue that 'ritual may be divisive as well as cohesive, and other notions besides social solidarity may be symbolically expressed by means of it' (Beattie 1964: 217)[5]. Either way, ritual affects the dynamics of society, or at least the group of people who participate in it. In this sense, ritual is 'socially loud', and calls for public attention. Parkin distinguishes ritual from custom in terms of public attention. He explains that 'custom is silent and, if properly carried out, unnoticed' (1992: 15). 'As the obverse, ritual is culturally loud and vibrant even when acoustically mute and tranquil' (ibid.). Therefore, whether or not a ritual is performed properly is what attracts the public gaze. Lewis (1980: 19) states that 'what is clear and explicit about ritual is how to do it—rather than its meaning'. The people he worked among knew how to conduct ritual. They noticed when it went wrong, but they could not readily explain what was being expressed, communicated, or symbolized by the ritual. What matters is the proper performance of ritual. An

audience to judge the quality and conventionality of the performance is also indispensable to ritual performance (Watson 1988: 6). Additionally, since the proper demonstration is of central importance when conducting a ritual, the mental state of the participants, their personal beliefs, and predispositions are not given much weight (Watson 1988: 6; Lewis 1980: 26).

Turner (1968: 2) suggests that each type of ritual represents a 'storehouse of traditional knowledge', and is an 'aggregation of symbols'. The symbols of ritual are 'regarded as multi-faceted mnemonics, each facet corresponding to a specific cluster of values, norms, beliefs, sentiments, social roles, and relationships within the total cultural system of the community performing the ritual' (Turner 1968: 1-2). Therefore, ritual symbols express something more than they seem to, or even something other than what they are. Ritual symbols transmit many things to ritual participants who are able to decode them.

Douglas (1966) points out that all margins and beings in a marginal or transitional state are polluted, because they are neither in one state nor in the next; they are undefinable, dangerous, and unclean. She describes how ritual is enacted in order to resolve anomaly. Ritual is considered to have the power to avoid the threatening quality and uncertainty caused by the dangers of pollution. Ritual is, therefore, conducted to control uncertainty, crisis or chaos, so that people can be released from the feeling of powerlessness in crisis (Matsuoka 1997: 47).

For Leach (1970), almost any kind of action has ritualistic and technical aspects. At one extreme there are actions which are rational and for entirely pragmatic purpose; but at the other there are actions which are strictly aesthetic, technically non-functional. 'Between the two extremes we have the great majority of social

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[5] See chapter 6 in Geertz (1993) for an example of a ritual that tears the society apart rather than integrates it.

actions which partake partly of the one sphere and partly of the other' (Leach 1970: 13).

2.2. Medical routines

Clearly then, there is no possible agreed definition of ritual. Furthermore, according to the discussion above, it seems difficult to interpret medical routines at the PCU as ritual, since activities taken place at the PCU are primarily associated with rational and scientific effect, and direct overt technical result is expected by the participants. Leach's definition, however, lends itself very well to my idea. Medical routines include both aspects; a pragmatic, practical aspect and a ritualistic aspect which is repetitive, transformative, symbolic and has the power of control. I will demonstrate the ritualistic aspects of medical routines in the following sections. However, I wish to retain the word 'routine', which combines ritualistic and technical aspects, in the following discussion.

2.2.1. Socially loud actions

Actions taken at the PCU are socially loud—they are not merely matters between the patient and the doctor. Every single treatment given to a patient is explained, not only to the patient him/herself but also to his/her family members, and is reported to other staff at daily conferences. It is very important for all the health professionals to roughly grasp all the patients' conditions[6]. The effect of the treatments or the actions taken by the patient (i.e., returning home for a short while) is

of everyone's interest at the PCU; it is exposed to the public gaze. The outcome is judged not only by the staff and the patient, but also by the family. This is the case especially when the patient is not in conditions to communicate properly.

By sharing patients' information with all the staff, better team care is supposed to be provided for the patients (i.e., good symptom control, good relationship between the patient, the family, and the staff, and good support to help the patient achieve unfinished tasks).

2.2.2. Symbolic and multi-faceted natures

Many treatments given to the PCU patients have symbolic and multi-faceted natures. For example, the usage of morphine is not only one of the methods of pain relief but also implies imminent death. When I observed a doctor's meeting with the patient's family, the family was insisting that the doctor should not tell the patient that he was using morphine. According to the family, the patient used to say that it was the end of his life once morphine was administered to him; for him, morphine was the last resort and directly related to imminent death.

Morphine is administered in a variety of forms. The oral route is the preferred method for giving morphine; however, if the patient is unable to tolerate this (e.g., a dosage becomes too much to take it orally, or he suffers from dysphagia due to physical deterioration), a change is normally made to a continuous subcutaneous infusion which comes with a portable battery operated syringe driver (Saunders *et al.* 1995: 20). Continuous subcutaneous infusion is usually used by patients whose

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[6] At the PCU in Higashi Sapporo Hospital, each nurse has two or three patients in his or her care; however, at staff conferences all nurses are expected to be aware of all patients' conditions. This is probably because patients are all at the terminal stage of their life, and any nurse should be ready to provide careful nursing at these critical times.

physical condition is too deteriorated to take morphine orally; consequently, it is again connected directly with imminent death. At the PCU, I heard some volunteer workers saying, 'Ah, Mr X is finally having a morphine infusion. He has reached the terminal stage at last then...', when they saw the patient with a continuous subcutaneous infusion for the first time. I also observed the conversation between a female cancer patient aged 72 and a nurse:

> Patient: I don't want to have a tube on my body, as I know I would get weaker if I did.
> Nurse: No, it's not true.
> Patient: I saw many patients who got worse after having a tube inserted. So I don't want it.

For this patient, a morphine infusion is directly associated with severe physical deterioration. In this manner, for some patients morphine implies severe physical deteriorations or even death, but it is also true that others perceive it as a miracle drug to relieve most cancer pain—morphine is a symbol of pain relief. A doctor at the PCU once told me that when he explained to his patients an effect of morphine on cancer pain they always looked so relieved and happy to know about it. Morphine has two different symbolic meanings for patients.

Some patients also wonder whether their time is limited when the PCU staff start to enthusiastically suggest that they return home for a short period. It is routine for the staff to suggest that patients leave the PCU for a while. Sometimes, however, PCU staff encourage patients to return home because they acknowledge that the patient's condition will shortly deteriorate, and the patients would otherwise miss the last chance to have a good time with their family at home. I observed a patient at the PCU saying the following to his family member.

My doctor persistently asks me if I want to return home for a few days.

Am I soon dying?

Some patients sense that they are in a relatively good condition for the last time in their life, when asked if they wish to return home.

The multi-faceted nature of routines may work negatively by causing misunderstandings about treatment between the patients and the staff. However, this aspect of routines may be also useful if the staff wish to let the patients to understand their condition without explicitly telling them they are dying soon. In this sense it can be said that this aspect of routines works to maintain a good relationship between the patients, their family, and the staff.

2.2.3. Symbolic and repetitive actions

There is a routine of *inchō kaishin*, the hospital director's round, at the PCU at Higashi Sapporo Hospital. As explained in chapter 1, on Tuesday morning, staff from outside the PCU, such as the hospital director, the director of nursing, deputy directors of nursing, in addition to the PCU staff, go around all the PCU patients. The size of this group is usually approximately ten or more people. For the PCU staff, the hospital director's visit is a very important weekly event, and it usually takes priority over the principal work at the PCU. Although the scale of the event is so large, and it is also treated importantly by the staff, what the hospital director exactly does during the round is little more than greet the patients[7]. It is probably meaningful for the patients to meet the top person in the hospital and for the hospital director to grasp the real state of the PCU patients; however, there is no definite reason to explain why this is

[7] The official reason for the hospital director's round is for the director to have an accurate grasp of each PCU patient's condition.

carried out weekly, on a certain day at a certain time, why the group is so large, and what this routine means to the PCU. Nothing is more significant than carrying out the routine properly[8]. Although the visit amounts to nothing more than greeting the patient, many patients are extremely pleased to see the hospital director: exchanging even a few words with the hospital director means so much to them. Together with the fact that all the members of the group are in white coats, which differentiates them from patients and their family, the hospice director's round at the PCU also includes a symbolic image of authority.

This case shows that repetitive actions provide the feeling of reassurance. The regular hospital director's round may help to relieve patients' anxiety because patients feel that their condition is regularly grasped by the top person in the hospital. It may also reassure both the hospital director and the PCU doctors because it is important for them to give patients the best treatment agreed by the hospital director. The hospital director's round is an opportunity for the medical staff to obtain the director's approval for their treatment. The hospital director may also be reassured by communicating with the PCU patients directly so that he can learn if they are satisfied with the treatment given. In this way, the hospital director's round helps to establish good relationship between the staff and the patients and to provide the patients with the best possible care.

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[8] The group of the hospital director's round looks like a procession. The director walks at the head of this 'procession', followed by the PCU doctors, the director of nursing, deputy directors of nursing, and a number of other staff. Outside the patient's room, the PCU doctor quickly picks up the patient's medical chart and hands it to the director so that he can understand his/her condition. He gives the medical chart back to the doctor, then they enter the patient's room. The doctor writes clinical matters down on the chart, while the director talks to the patient. After this, usually the nurses and the medical social worker say a word to the patient, and then the whole group leave the room. This is repeated until they see all the patients at the PCU.

2.2.4. Control of chaos

At the PCU, it is generally difficult to predict what will happen to patients even in the nearest future; therefore, they are often considered as 'menacing entities'. This threatening quality of the patient's state is firstly controlled by naming the pain and symptoms, since 'to name the origin of the pain is to seize power to alleviate it' and 'is also a critical step in the remaking of the world' (Good 1992: 45). Especially for the medical staff, it is important to diagnose pain and symptoms in order to determine the next action to take. Once pain and symptom have been identified, the patient's state becomes less uncertain and unpredictable, and more importantly, now the staff simply have to follow guidelines. When I was conducting fieldwork, I sometimes heard the doctors diagnosing some patients' mental problems simply as 'adaptation disorder'. For example, at the staff conference, I heard two PCU doctors conversing as follows.

> Doctor 1: I though her depression would become better as time went by, but... Medication might help her, though.
> Doctor 2: She should see a psychiatrist. She may suffer from an adaptation disorder.

Those doctors were discussing the case of Ms Matsuyama (see chapter 6). As discussed before, Ms Matsuyama was socially withdrawn and severely depressed. For the PCU doctors, her state was beyond their control, and they were perplexed with it. It seems that by diagnosing the symptom as 'adaptation disorder', the doctors wanted to make it clear that the symptom was untreatable at the PCU. Ms Matsuyama's depression was ignored for 'good' reason by the PCU doctors, who were then able to concentrate only on their primary mission (i.e., relieving patients' physical pain).

The most prominent example of the medical attempt to control chaos is sedation. Sedation is defined as a medical procedure for relieving patient's distress by intentionally reducing the level of consciousnesses, intermittently or until the end (Hamaguchi *et al.* 1999: 89; Tsunetō 1996: 257)[9]. Morita *et al.* (2001: 335) further point out that terminal sedation is used when 'intractable or severe distress refractory to standard palliative treatment' is present. Terminal sedation is, therefore, conducted as the last resort when the patient's condition becomes totally out of control.

At what point to commence sedation is still controversial, especially in the case of terminal sedation (Ikenaga 1996; Hamaguchi *et al.* 1999). For example, the PCU at Higashi Sapporo Hospital indicates three conditions for the application of terminal sedation; (1) the patient cannot stand the pain and distress refractory to standard palliative treatment; (2) if awake, it is anticipated that the patient would suffer more pain than he does at present, and that he would not be able to endure it; and (3) the patient wishes to receive the treatment (or the patient would so wish if he or she had the capacity for decision-making) (Hamaguchi *et al.* 1999: 92). Even if the patient or the family requests sedation, the doctor does not carry it out unless other conditions meet the criteria[10].

It seems that sedation is also conducted when the medical staff feel powerless and helpless. This is the only way for the staff to control chaos at this stage. For example, a 50-year-old breast cancer patient, Ms Ogawa, was suffering insomnia, which is one of the symptoms of advanced cancer. She kept saying to her doctor that she would like to sleep 'deeply', and then finally started to ask him for sedation, since she felt it was too painful to live any more. Considering her physical condition, the

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[9] Sedation is required when patients suffer from dyspnea, pain, general malaise, agitation and nausea. About one-half of sedated patients suffer more than one symptom (Morita, *et al.* 1996: 36).

doctor judged that it was time to administer sedation. Ms Ogawa, however, hardly complained about her distress to her family. When the doctor had a meeting with Ms Ogawa's family, her husband said;

> She has never said anything like that [she feels too much pain to be able to live any more] to me. She says that she wants to sleep better, and talking tires her. We have a normal conversation. [...] She has never whined to me. She says only something like 'Today I've been...', although she says she is exhausted.

The doctor then replied:

> These days, we have been giving her treatment [in order for her to sleep] only when she feels so, but if she says she would like to sleep until the end... Well, we can remove the cancer pain, but not other pain..., there is a particular pain for cancer, which needs to be removed... When it is clear to everyone that she is suffering, and if she wants us to do something, that [terminal sedation] is the only means... It seems that she worries about you and says to you that she would like to recover to repay you for your kindness. It also seems that she hasn't complained to you, but when I saw her earlier, she told me so [that she would like to sleep until the end], although her son was present.

The doctor was obviously suggesting to the family that Ms Ogawa should be administered permanent sedation soon. It was probably very upsetting for the doctor to hear Ms Ogawa saying that she wanted to sleep without waking up again, every time he went to her room. Her physical condition was so deteriorated that he could not help feeling powerless and useless. The only way the doctor could take control over this situation was to sedate the patient. In so doing, he may have felt more useful and relieved. Furthermore, he did not have to hold any more meetings to discuss the

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[10] See the case study of Mr Hanazono in chapter 6.

patient's condition with the family, he did not have to talk to the distressed patient, and he could also concentrate on other patients. Sedation enables the doctor to make everything more predictable and under better control; namely to sedate a patient heavily makes him or her 'docile' for the staff (Lawton 2000: 119). It also helps the institution to run more smoothly. Sedation creates no fuss and uncertainty.

Matsuoka (1997), who carried out fieldwork at a maternity hospital in Japan, points out that medical routines are carried out not only to avoid uncertainty but also to increase the efficiency of staff labour at an hospital, as routines are the safest and easiest treatment for the medical staff who often confront uncertainty and danger (Matsuoka 1997: 46-47). 'Within the context of medicine, the more routine treatment is carried out, the less uncertainty and unknowns the staff encounter. Additionally, this results in efficient labour of the staff [since routines are the treatment which the staff are most used to] (Matsuoka 1997: 47)'.

Katz (1987), who conducted fieldwork at a hospital operating room in the United States, suggests that medical routines (which she calls rituals) 'define categories and clarify boundaries between important states by exaggerating the differences between them, doing so precisely where the boundaries normally are not clear and well-defined' (Katz 1987: 349). In the case of Ms Ogawa, her status before sedation was very unclear and ambiguous for not only for doctors but also for her family members. For example, Ms Ogawa's husband said:

> We can't get her back once she is deeply sedated... I hope she can spend some good time, even a day longer, but she seems to have much pain now... *I don't know what to say to her.* I can't say, 'Do your best' to her either.

> I know we will have to take the best way for her in the end. [...] I want to see her alive for even an hour longer, but there is agony for her, too. *I know we should draw a clear line somewhere.*
>
> (emphasis added)

For her husband, Ms Ogawa was in an ambiguous situation—she was not dead yet but not living as before. He still wanted to treat her as alive, but at the same time he did not know what to say to her. He wanted her to live longer, but he knew that she was suffering unbearable pain. Six days after this conversation, as her physical deterioration was accelerated, the doctor suggested to the family that it was time to administer heavier sedatives to Ms Ogawa. At this point her family started to contact relatives who lived far away so that they could see her on her deathbed. Ms Ogawa died two days after she was sedated.

In this case, administering heavy sedatives to the patient clarified her ambiguous status. Before sedation, Ms Ogawa's condition confused both her family and the doctor. After sedation, however, she was soon recognized as a person who was not going to be awake again. Sedation clarified and regulated the ambiguous situation, and this helped the participants decide which action to take next. Philpin (2002) argues that ritual aims to protect the participants from stress and anxiety, and to maintain the social order of the given environment. Sedation lessens the level of anxiety caused by ambiguity and suppresses turmoil, which helps to keep the social order at the PCU. In this sense, it can be said that sedation is the last resort to solve the patients' social death, which disturbs the social order at the PCU.

2.3. Death and transformation

As shown above, medical routines conducted at PCUs have various ritualistic aspects. In this section, I will explore transformative aspects of transitional period in order to further understand characteristics of medical routines conducted at the PCU.

A patient with a minor illness is normally expected to return to his/her previous status when he/she recovers after the hospitalization, thus there is no transformative quality during the hospitalization. On the other hand, a terminally ill patient is not able to go back to what he/she used to be; his/her status changes irreversibly. In this sense, the period of PCU stay involves a transformation of the patient's status. It can be said that medical routines shown above at the PCU are carried out in order to successfully 'transform' the patient from the sick to the dead.

In some societies, the illness experience itself transforms the patient from one status to another. For instance, among the Ndembu, who live in Zambia, certain rights of participation and certain roles are only given to those individuals who have gone through a particular illness and its treatment; namely to those who have survived affliction (Turner 1968). On the other hand, among the Gnau in New Guinea, even if an individual survives an illness, he returns to his previous status and does not take on a new one (Lewis 1976: 74). Lewis attributes this to the absence among the Gnau of the view of affliction acting as a transformative power. This tendency—whether to view a particular illness as affliction or not determines one's status after being cured—is also seen in modern society. For example, individuals who recover from minor illness (e.g., appendicitis) are usually not given a new status when they come back to society from hospital. In the case of more serious illness such as cancer, however, survivors are regarded as different from before and sometimes become the

man in the news. Lance Armstrong, the world-class cyclist, who was diagnosed testicular cancer at the age of 25, is one of such examples. When his cancer was found it had already spread to the brain and the lungs. He went through a surgical operation as well as aggressive cancer treatment. Two months later, he miraculously recovered from cancer. He then created the Lance Armstrong Foundation, and since then he has been working as a leader for cancer survivors and a world representative for the cancer community (Yomiuri On-Line 2004; Lance Armstrong Foundation 2005).

When affliction is regarded as a means of transformation, it plays an important role for many illness sufferers and those around them. For instance, when the individual who has traumatic experiences is healed by a shaman, and survives the affliction, he or she then comes to have access to the powers of a shaman. Not all such individuals become shamans, but all shamans have at some point experienced the initial affliction (I. M. Lewis: 1971; Parkin 1991)[11]. Among the Tungus reindeer herders of Siberia, possession by pathogenic spirits, which is their common explanation of illness, is 'the normal road to the assumption of the shaman's calling' (I. M. Lewis 1971: 54). Becoming a sufferer acts, in other words, as an initiation into the shamanic realm. Healing a sufferer is carried out for the sufferer as part of the cure; however, the practice is implicitly conducted as a means of training for the sufferer to become a shaman (Matsuoka 1994: 286). In the case of Lance Armstrong, his cancer experience transformed him from a cyclist to a leading advocate for cancer survivors[12]. In this case, Armstrong himself is not involved in curing other cancer patients; however, his name value and story of his survival from cancer enabled him

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[11] Namihira (1993: 77) notes that there are two kinds of shamans, those who have had undergone a suffering experience and have recovered from it, and those who learn to be a shaman. For example, the Manchurian Tungus select a child, and bring him/her up to be a shaman. However, if the child does not in due course experience trance states, people no longer support him or her (1993: 83).

to raise contributions to supporting cancer survivors and cancer research (Yomiuri On-Line 2004). His story also encourages and helps many cancer patients live with hope. In this sense, it can be said that he also has the therapeutic power analogous to what a shaman has.

The power of affliction is, therefore, dynamic. Matsuoka (1994) describes the case of a woman with fox possession in Japan, and examines how she subsequently became a shaman. This woman believed that she was possessed by a fox. However, while she was receiving a shaman's service for the possession and practicing asceticism to get rid of the fox spirit from her body, she began to gain shamanic power herself. Soon the signs of possession disappeared, and she was left with the shamanic power that she gained through asceticism. For her, 'her illness and asceticism were the rite of passage to become a shaman' (Matsuoka 1994: 279-280). This woman managed to control her chaotic state, and in so doing she could find a way to reintegrate herself into society (i.e., as a shaman). Had she not succeeded in this, she would have been segregated by society and viewed as a senseless mad person. For her, transforming into a shaman was the only way to rejoin society (Matsuoka 1994: 287).

Similarly, the process of dying involves not only the physical transformation of the patient from the sick to the deceased, but also the illness experience and affliction itself. At admission to the PCU, patients are separated from society, and the fact that they are dying remains with them whatever they do. Assessing the significance of their illness is the only way to accept it not as a meaningless chaotic

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[12] Even after he came back from cancer, Armstrong still takes an active part in cycling world championship and won the Tour de France six times consecutively from 1999 through 2004 (Lance Armstrong Foundation 2005).

state, but as a meaningful experience (Matsuoka 1994: 287); otherwise, death would have no purpose, and would be considered bad.

It seems to me that the hospice philosophy of a good death is implemented to give a meaning to one's illness and death. The dying experience is lonely, sad, and chaotic; however, it can be considered good when the patient overcomes the suffering and gains an ability to control the chaos. Then, the patient's death becomes something meaningful and acceptable by the family and the staff. The dying process at the PCU involves the transformation of the patient's status from the sick to the dead, but more importantly, it involves the transformation of death from a potentially bad one to a good one. Like the woman possessed by a fox in Matsuoka's example above, PCU patients are also able to become acceptable or even admirable entities through the experience of overcoming their affliction; otherwise, death can be just a mere draining experience for all involved[13].

Unlike in the shaman's world, at the PCU those who die a good death do not become a carer. Moreover, the PCU staff have not themselves gone though the affliction and achieved a good death. Some people seen by the shaman gradually gain the shamanic power to control chaos, while at the PCU, the patients' condition gradually deteriorates and they lose the ability to control their process of dying, and thus they become more dependent on the carers. Additionally, the patients themselves are considered as menacing entities, since it is difficult to predict what will happen to them at the next moment. These facts encourage the intervention of medical control.

During the dying process, the patients' status changes from the sick to the dead. More importantly however, the quality of death is also transformed into a good

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[13] The hospice doctor Yamazaki (1999) writes a chapter entitled 'All the dying were my teachers (*Shini yuku hito ha subete boku no shishō datta*)' where he introduces a breast cancer patient's death.

one. Death is considered potentially bad; therefore, in order to make a death good, menacing aspects of the patients should be firstly removed. In this sense, one of the characteristics of the medical routines, controlling chaos, plays a significant role during the process of dying.

2.4. Who needs routines?

Medical routines (especially ones with an aspect of controlling chaos) are by and large carried out so that the patients can transform death into a positive experience (i.e., a good death). In this sense, medical routines are perhaps enacted partially for the sake of the patients.

Routines also save the staff's time and institutional resources. As this leads to the smooth running of the institution, staff always tend to carry out medical routines. This tendency is seen not only in a context of palliative care, but also seen in different medical disciplines, such as obstetrics.

Martin (1987) describes how childbirth in the United States is controlled by routines and manuals to manage disorders. For example, obstetrics handbooks list the 'proper' management of disorders caused at childbirth. The uterus is meant to make a reasonable progress with a certain pace, like a machine. In the obstetrical literature, a woman's labour is subdivided into many stages and substages, like factory labour. Each of these is 'assigned a rate of progression based on a statistical study of the rate characteristic of 95 percent of labours in the study' (Martin 1987: 59). Rates deviating from these are considered to be disorders, and obstetrics handbooks demonstrate how to manage these disorders. For instance, in one handbook there is a chart which 'shows graphically how many are the paths through arrest and protraction to caesarean section and how few the paths to vaginal delivery' (1987: 59). All those

processes that fail to follow the path to vaginal delivery are considered abnormal and result in caesarean section. The chart helps obstetricians define the woman's (or the uterus's) condition easily and decide which action to take next. This saves the time of the medical staff as well as resources at an institution. Following the manual and conducting routines also reduces the obstetrician's fear of uncertainty[14].

Similarly, Matsuoka (1997) describes how childbirth is routinized in Japan. Matsuoka explains that routines, such as Kristeller (pressing the pregnant woman's abdomen to help the baby come out), episiotomy (the birth cut), labour induction, and caesarean section, are conducted in order to make the process of childbirth smooth for the hospital staff. With regard to an episiotomy, the majority of women who had it believe that it was a necessary treatment for them to give birth. It is, however, conducted mostly because it is easier for the staff to stitch up the cut made by an episiotomy than the torn wound which naturally occurs during childbirth (Matsuoka 1997: 44). Once again, the routines are conducted for the benefit of the staff and the institution.

In the realm of hospice care, many routines are also carried out for the sake of the staff and the institution. The doctor's round (*kaishin*) is a good example. This is practiced at the doctor's convenience, not the patient's. At Higashi Sapporo Hospital the hospital director's round on a Tuesday morning is especially a time-set routine, and time is certainly not set for the benefit of the patients. Those who do not feel well or who have something else to do (i.e., taking a medical examination in another room, or being taken to the bathroom by a caretaker) simply miss the hospital director, and

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[14] In this situation, the woman's state of mind is easily disregarded. For instance, when a woman's labour slows down because her contractions are not sufficiently strong, most obstetrics text attributes this to biological reasons, such as a too small pelvis (Martin 1987: 62). 'Nowhere is it suggested that the woman's general state of mind (fear, anxiety) might have led her to stop her labour, even though "*in many—perhaps one-half—of instances the cause of uterine dysfunction is unknown.*"' (Martin 1987: 62).

cannot see him until the next week. He will not be coming back to see those patients whenever they are available. The round should be conducted as planned, otherwise other scheduled plans will be disturbed.

Another example of medical routines in palliative care is a surgical operation to ease the patient's condition. Aforementioned uterine cancer patient, Ms Yasukawa, for instance, had trouble with bowel movement, as her enlarged uterus put pressure on the large intestine. Her bowel movement was fairly well controlled by a purgative; however, her doctor suggested that she undergo an operation to have a stoma (an artificial anus on the abdomen). A stoma would solve problems related to Ms Yasukawa's bowel movement, but at the same time, this would also reduce the staff's work load: they would not have to look after Ms Yasukawa carefully in order to prescribe purgatives in accordance with her day-to-day condition. Ms Yasukawa, on the other hand, was not happy to have another tube in her body. She was also afraid of her physical condition which might get worse due to the operation. In the end, she decided not to undergo the operation, yet I remember that the doctor was very keen on the operation.

Routine treatments, however, sometimes work for the benefit of the patient. In the case of childbirth, Matsuoka (1997) points out that routinized episiotomy actually prevents new mothers from worrying about their vaginal size. As a result of the frequency of episiotomy, many new mothers believe that it is impossible for any women to deliver a baby through such a small place. Therefore, women who deliver a baby without having an episiotomy feel embarrassed, as this might be taken to suggest that they had a wide and loose vagina. The universal practice of episiotomy lessens the fear and anxiety which women may otherwise experience. Similarly, at the PCU, I observed that every time the doctor explained terminal sedation as a means of pain

relief, both the patients and the families looked very relieved to hear about it. Knowing that the PCU usually conducts terminal sedation reduces some of the fear and anxiety that the patients and their families have regarding the dying process.

In this manner, medical routines are not only for the benefit of the staff and the institution, but also good for the patients. However, I cannot help remembering what Dr Hirano from the Bihāra at Nagaoka Nishi Hospital said to me:

> If there was a manual for cancer treatment, the medical staff could take an easy course. But I think it is very important to have a hard time with the patients in the decision making process [while asking ourselves] "What can we do?", "This treatment is good, but it causes side effects", and so on. To be extreme, I think it is alright even if the patient dies while he and the staff are having a hard time in deciding the best treatment for him.
>
> (H Hirano: personal communication, September 6, 2000)

Dr Hirano also said to me, 'I believe that sharing a hard time together is another way of healing.'—for him, nothing is more important than sharing time and suffering with the patients. Medical routines, however, take this opportunity away from the process of hospice care, and enforce the 'quiet death with no fuss' (McNamara 2001: 106) which is closely linked with the good maintenance of the organization.

3. Towards the end of life

In this section, I look at the moment of biological death, that is to say, the end of the dying process at PCUs. I briefly examine how it occurs, and what kind of routines is conducted at this stage.

During my stay at Higashi Sapporo Hospital I experienced a patient's death once. This was that of Ms Yasukawa, aged 36.

When Ms Yasukawa was at the critical stage, I received a beeper call from one of the doctors. As soon as I heard the news, I ran into her room, but she was already dead, and all her family members were crying over her at her deathbed. On my arrival, the doctor in charge and some nurses came into the room. The doctor asked:

'OK, Ms Yasukawa, may I examine you now?'

He listened to her chest, took her arm to take her pulse, and then looked into her eyes, and said to her family:

'I am afraid she is dead. The time of death is 10: 36.'

After a few quiet words with the bereaved, the doctor made his exit. Three nurses proceeded to quickly remove the many tubes which connected Ms Yasukawa to the medical devices, without saying a word. During that time, each member of the family was sobbing and took it in turns to talk to the dead patient.

'Next time when you are born, I hope you will have a much healthier body.'

'You can now take it easy…'

'You can finally come home with us now…'

'You've done your best.'

[to me] 'She made her farewells to all at her last moment, although she was in pain. She tried with all her strength, you know.'

All the tubes, which had been helping her live, were removed from her body at last, and she became totally free. Then she looked just like a human being, or say, a member of her family, not a 'patient' anymore for the first time since her hospice admission.

Patients who die at a PCU are usually taken to the bathroom for cleansing, and then a funeral company car comes to collect the body. The body is, however, usually taken back home first and left there for a while before being taken to the funeral parlour. Many patients go home for the first time after their admission when they physically expire at last.

4. Summary

In this chapter I have explained how death is attempted to be made good at the PCU in Japan in order to fill the gap between the hospice ideology of good death and reality.

As discussed in chapter 6, social death is considered bad. During the dying process, therefore, much effort is being made to stop patients to die socially long before physical death and to improve the state of those who are already socially dead. Medical routines conducted during this period aim to control chaos caused by bad death and dying and to maintain the social order at the PCU. In practice, medical routines provide good symptom control, good relationship between the patient, the family, and the staff, and good support to help the patient achieve something that remains undone, so that the patients can live as themselves until the end. Death is attempted to be made good and transformed into a meaningful experience during the dying process at the PCU.

In this chapter, however, I have demonstrated that medical routines also simplify the care for the dying. This fact helps to save the time of the staff and institutional resources; however, this tendency takes away from patients and staff the

chance to discuss problems and to share the difficult time together, and creates the idea at PCUs that a 'quiet death with no fuss' (McNamara 2001: 106) is good.

In the context of the hospice culture, to accept death and dying as a normal process of life does not necessarily mean that death is always accepted by everyone regardless of its quality. In practice, death may be accepted only when it is perceived as good. Hospices and PCUs were originally developed to provide more humane care to those who die alone and in pain. Yet, what they provide is a place and time to transform death, which is considered bad and dreadful as it is, into a 'good' one (within the context of medicine and the institution), rather than practicing purely patient-centred care. Death needs to be made good so that it can be acceptable by all. The patients are also accepted by the carers more easily when they transform or are transforming death into a good one. Therefore, it can be said that the period of staying at a PCU is a transitional period where the transformation of a death into a good one is performed.

As discussed in chapter 3, this transitional period at the PCU can be inserted into the process of death rites in contemporary Japan. Contemporary funeral rites in Japan emphasize the stage of incorporation, and lack the stage of transition which used to be the most important stage in traditional Japanese death rites. The funeral rite in traditional Japan was full of rituals to control the soul of the dead and to send the soul, without fail, to the next world. In contemporary Japan, however, the dying process at the PCU, where the patients are controlled by the staff and medicine in order to transform death, without fail, into a good one, plays the role of a transitional period.

At the funeral ceremony the deceased's life is beautified by the memorial address (*chōji*) which intends to make a funeral good (Suzuki 2000: 214). It can be

said that 'the objective of the funeral industry is to generate an occasion for remembering only the virtues and merits of those who have died. The faults of the deceased in his or her lifetime may be amended, resolved, and forgiven by the participants at a good funeral' (Suzuki 2000: 214). A good death helps the bereaved produce a good funeral, and even a so-called bad death can be amended and made good during the ceremony[15]. Whatever happened to the dead, their death is made good before they are finally laid to rest. The dead, then, incorporate into the world of the dead smoothly and safely.

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[15] In traditional rituals, a balanced relationship between the living and the deceased was maintained due to belief in the dangerous spirit, which was considered to exist until the 49th day after death. However, in contemporary funeral rites, the living have more power. They evaluate the deceased's life and decide how much honour should be given to the deceased (Suzuki 2000: 214).

Chapter 8: Development of Hospice and Palliative Care in Japan

So far we have been looking at how hospices and palliative care units function in Japan from the insider's point of view, i.e., people engaged with hospice and palliative care, such as health care professionals and patients. We have examined hospice philosophy, including the idea of a good death, and have discussed the care and treatment that health care professionals provide to their patients. The increasing routinization of medical treatment has led to hospice care becoming more institutionalized, and the concept of 'good death' within the context of the hospice philosophy does not seem to be purely beneficial to the patients but also to the medical professionals and the institution. The ideal might even seem to constrain the patients' dying patterns. The good death philosophy was originally developed in opposition to institutionalized deaths at hospitals; however, in effect, it seems to end up generating a new form of 'institutionalized' death within the hospice culture.

This chapter attempts to examine the development of hospice philosophy and its permeation in Japan from the several different points of view, i.e., from the viewpoints of the hospice leaders, the government, and the public. First of all, I will illustrate the historical background of the hospice movement in Japan, what the early hospice movement leaders advocated, and how it was accepted by the society. Then, how the Japanese government has supported the hospice movement will be considered, followed by an examination of the reaction of the public to the movement.

The analysis in this chapter will help us further understand what the hospice advocates, the government, and the public in Japan require from palliative care.

1. Historical background

The modern hospice movement began in Britain in the 1960s and soon spread to other Western countries such as the United States. The hospice philosophy was introduced into Japan in the 1970s. In this section, we will look at the social background before the movement was introduced and how the movement has influenced modern medicine in Japan.

1.1. Before the hospice movement

Chapter 1 briefly discussed the way in which medical technology has dramatically developed throughout the last few centuries in the West, and suggested that this has led to an increasingly high-tech oriented approach to care in the realm of medicine. Japan is no exception in this regard. Soon after the Second World War, various infectious diseases were rampant in Japan; however, the introduction of antibiotics and improvements in housing and food suppressed the menace of infectious diseases by the beginning of the 1950s (Shinmura 1998: 173). Antibiotics cure acute diseases effectively, prolonging life expectancy, and this fact provided the illusion that any disease might be cured by medicine.

Under these circumstances, since 1955 infectious diseases which need only a short-term hospitalization have been replaced by lifestyle diseases (e.g., cancer, heart disease, and diabetes) which are more chronic and possibly need long-term hospitalization (Shinmura 1998: 173). The number of hospitals rapidly increased

throughout this time, and in the 1960s and 1970s Japanese medicine became increasingly oriented toward high-technology diagnosis and treatment (Long and Chihara 2000, Long 2001a). It also became strongly cure-oriented, and terminally ill patients tended to be given too much curative treatment even in the final stage of life (Kashiwagi 1991: 95). These tendencies can be explained by a national health insurance system which at that time was based on a schedule of fees for service and payment by results. Under these circumstances, invisible factors in care, such as payment for psychological support, were not sufficiently covered by insurance (Kashiwagi 1991: 95).

As the number of hospitals increased, the number of deaths occurring at hospitals also increased. Vital statistics on trends of death by place of occurrence show this tendency very clearly. In 1951, only 11.6 % of deaths took place in hospital (82.5 % in the home), however, in 1977, the rate of hospital deaths overtook that of home deaths (50.6 % and 49.4 % respectively). The rate of deaths which took place in hospitals increased continuously to 83.3 % in 2000, and only 16.7 % of deaths in Japan took place in the home in 2000 (Statistics and Information Department, Minister's Secretariat, Ministry of Health, Labour and Welfare 2002: 137)[1]. Death has been, therefore, increasingly removed from the home and treated at hospital within the context of medicine; i.e., death has become medicalized. Death has also been removed from everyday life, and the opportunity for the younger generation to see someone dying has dramatically decreased.

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[1] The numbers of both hospitals and hospital beds peaked in 1990, and they have been decreasing since then. This, however, does not contribute to a decrease in hospital deaths. Sinmura (2001: 9) explains this tendency as follows: (1) Japanese people still depend on medicine at hospitals too much; (2) the system to prepare for home deaths is not fully facilitated yet; and (3) both the family and the staff from welfare facilities feel insecure at a patient's home deathbed.

Disease patterns have been changing rapidly, and this has led to a gap between the ideals of dying and the practice of medical care (Long and Chihara 2000, Long 2001a). From the Meiji era (1868–1912) to the beginning of the Shōwa era (the 1950s), the major causes of death were infectious diseases, such as tuberculosis, pneumonia, and gastroenteritis. In the latter half of the 1950s, however, the number of deaths caused by these infectious diseases rapidly decreased, and a malignant neoplasm (cancer), heart disease, and cerebrovascular disease have now become the major causes of death (Statistics and Information Department, Minister's Secretariat. Ministry of Health, Labour and Welfare 2001: 10). Deaths caused by malignant neoplasms occupied 23.1 % of all deaths in 1981, and became the top cause of death in Japan—and this rate is still increasing (Health and Welfare Statistics Association 2001; The Ministry of Health, Labour, and Welfare Official Website 2003). The increase in such lifestyle diseases has changed the process of dying; more people are facing longer period of hospitalization with chronic or incurable diseases. Under such circumstances, the usual medical attitude that emphasizes 'cure' is no longer sufficient to cater to the needs of the patients.

In the late 1960s and the 1970s, scepticism about the professional competence of doctors increased amongst people in Japan. 'News stories of students buying their way into medical schools and physicians making money by prescribing large amounts of medication increased scepticism about whether doctors were worthy of the public's trust' (Long and Chihara 2000: 148). Moreover, doctors often prescribed excessive examinations and medications without sufficient explanation to, or consent from, patients (Long and Chihara 2000: 148). In 1985, a book called *The Book to Help You Understand Prescribed Medicine* was published to meet the demands of those patients who wished to know something about the medicine prescribed by their doctors. This

publication has been a best seller in Japan and has sold more than two million copies (Iryo Runessansu 2001). This suggests that up until that time informed consent had been hardly practiced in Japan (Mizuno 1997: 116), and that the public had become skeptical about doctors and wanted to receive more sufficient information on the treatment they received from doctors.

1.2. Introduction of the hospice philosophy

The hospice philosophy was introduced into Japan from Britain and the United States in the 1970s, 'in the midst of questions raised about the limits of technologically based care, a rising cancer rate, and deteriorating physician-patient relations' (Long 2001a: 276).

In 1973, the first hospice and palliative care service in Japan was established at the Yodogawa Christian Hospital in Osaka. It was called OCDP (Organized Care of the Dying Patient), and aimed to practice a team approach to the care of the dying (Kashiwagi 1991: 67). A psychiatrist, Tetsuo Kashiwagi, who is now the central figure of the Japanese hospice movement, was the founder of OCDP. Kashiwagi worked as a resident psychiatrist in the United States from 1969 to 1972. On his return from the United States, he opened a psychiatry department at Yodogawa Christian Hospital, where he was asked by doctors and surgeons to counsel terminal cancer patients who suffered with depression. Kashiwagi thought that he should establish a team similar to the ones he had seen in the United States, and asked other medical staff, chaplains and social workers to help him. Kashiwagi came across some English articles about hospice care in medical and nursing journals only after he started OCDP. In this sense, he started hospice care in Japan without having a thorough knowledge about hospices (Kashiwagi 2000: 109).

Soon, the work of hospices in England and the United States started to be discussed in newspapers and nursing journals in Japan. A strong concern about hospice and palliative care also began to grow amongst medical professionals, who visited hospices in England and the United States. In 1981, the first hospice in Japan, Seirei Hospice in Shizuoka, was established with 30 beds. The aforementioned Yodogawa Christian Hospital followed Seirei Hospice, and opened a hospice ward within the hospital building in 1984. The number of hospice and palliative care units increased rapidly, and in 2005 there were 150 of these institutions, with 2836 beds, in Japan (Hospice Palliative Care Japan 2005).

Those promoting the hospice movement in Japan in the 1970s saw the situation of Japanese terminal care as follows:

(1) Excessive treatment for life-prolongation was given to patients;

(2) Not sufficient attention to pain relief and symptom control was given;

(3) Patients were suffering loneliness. Doctors essentially abandoned them as there was nothing they could do to cure them;

(4) Insufficient patient autonomy was seen due to lack of practices of informed consent and truth telling

(Kuroda 1998: 194)

Hospice promoters introduced the hospice philosophy in order to improve the situation concerning the points made above and emphasized:

(1) An affirmation of death;

(2) Control of pain and symptom;

(3) Holistic care;

(4) Care of the family;

(5) Team care

(Kuroda 1998: 195–196)

As a consequence of the efforts of the hospice movement promoters, the number of hospice and palliative care units in Japan has increased dramatically, and the number of deaths taking place in these institutions has also been increasing every year (Ida *et al.* 2002: 182). In 1981, malignant neoplasms became the first cause of death in Japan (approximately 166,000 death caused by malignant neoplasms), and since then the number of patients who die from it has also been growing—approximately 310,000 people died from malignant neoplasms in 2003 (The Ministry of Health, Labour and Welfare Official Website 2003). Despite the growing number of hospice and palliative care units, the number of beds is still far less than the demand.

Apart from the establishment of hospice and palliative care units, many other related activities have taken place in Japan since the 1970s. The Japanese translation of *On Death and Dying* by Elisabeth Kübler-Ross was published in Japan in 1971 (Okayasu 1995: 2) and made a great impression on many people[2]. This translation has gone through more than a hundred impressions and it has remained popular in Japan

since its first publication (Suzuki 1999: 393). In 1977, three important events in the history of hospice and palliative care in Japan took place. Firstly, the Japanese Association of Clinical Research on Death and Dying was established. This organization was formed with a membership primarily of nurses and doctors, who were interested in terminal care. Secondly, Sōichi Suzuki (a doctor in a private practice in Tokyo) visited St Christopher's Hospice in London, and the works done at the Hospice was introduced in the newspapers in 1977 (Kashiwagi 2000). This was the first public report about hospices in Japan. Thirdly, in 1977 the percentage of deaths that took place in hospital (50.6 %) overcame that of home deaths (49.4 %) for the first time (Kashiwagi 1991: 95; 2000: 110).

As mentioned above, the first hospice in Japan was set up in Shizuoka in 1981. Ten years later, the Japanese Association of Hospice and Palliative Care[3] (whose head office was at Seirei Mikatagahara Hospital, under the chairmanship of Kashiwagi) was organized in order to improve the quality of hospice and palliative care units, and to spread hospice philosophy in Japan (Kashiwagi 2000:112). The Japanese Society for Palliative Medicine (housed in Higashi Sapporo Hospital under the chairmanship of Kashiwagi) was also established, and the Society's first Annual Meeting was held in Sapporo in 1996. 'This Society is thought to have been a basis for the development of palliative medicine in Japan. The Society aims to develop palliative medicine into a specialized scientific discipline' (Ishitani 1999: 62), in order

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[2] For example, one of the leading hospice doctors, Fumio Yamazaki, read this book while he was working as a ship's doctor and was very impressed with it. When he left the ship in 1984, he decided to throw himself into terminal care as a surgeon (Yamazaki 2000:1). He published his first book, *Byōin de Shinu to iu Koto* (*Dying in a Japanese Hospital*) in 1990, where he described his extensive experiences with terminally ill patients at a non-hospice ward. This book became a best seller (Davis *et al.* 2002: 228), and it was also made into a film in Japan in 1993. In his book, Yamazaki 'stressed the importance of dying patients not feeling alone and the need for hospice, which he defined as an institution where people continue to live their last days with dignity based on communication without falsity' (Yamazaki 1990, cited in Davis *et al.* 2002: 228).

[3] The name was changed to Hospice Palliative Care Japan in July 2004.

to bring up specialists in hospice care, and to keep hospice care progressing constantly in the field of medicine (Ishitani 1999: 62).

In this section, we have mainly seen how the hospice movement was initiated and what the hospice movement leaders achieved in Japan. In the next two sections, we will investigate how the Japanese government has supported the movement, and how the public has responded to the trend.

2. Governmental support

The hospice movement was primarily started by medical professionals, and hospice and palliative care continued to be practiced within the national health insurance system of the day, which was based on a schedule of fees for service and payment by result. However, palliative service, which emphasizes symptom control and psychological support of the patients, requires higher labour costs than treatments for curable diseases, and moreover, it was not sufficiently covered by insurance. Hospice and palliative care units were operating by receiving compensation on the same basis as other medical services[4]. It was therefore difficult for staff to manage hospices without donations (Kashiwagi 1991).

In order to increase the number of hospice and palliative care units, it was essential to prove that it was economically manageable to run such units (Kashiwagi 2000: 112). Accordingly, the Japanese Government made the decision to give medical insurance benefits to Seirei Hospice and Yodogawa Christian Hospital Hospice in April of 1990; and by the end of 1990, three other places were also given medical

insurance benefits from the Government (Kashiwagi 1991: 95; 2000: 112). The new insurance system certified hospice units if they met certain standards and government regulations (see section 2.1). Under this system, a fixed daily subsidy (25,000 yen per day in 1990, which was increased to 36,000 yen in 1998) is designated for each patient regardless of the cost. Therefore, the new system is not based on 'payment by results', but on providing a fixed amount per patient per day (Kashiwagi 1991: 96; 2000: 112). Since the new system was enacted, the number of hospice and palliative care units has increased rapidly.

2.1. Standardization of hospice and palliative care

In order to receive benefit from the Government (i.e., from the Ministry of Health, Labour and Welfare) hospice and palliative care units need to meet certain standards. The Government established these standards in April 1990, and a revised version appeared in 1998.

Standards for Palliative Care Units Facility

(1) Palliative care units are wards where patients at the terminal stage with malignant neoplasm or AIDS are hospitalized and receive palliative care.

(2) There are nurses working at the ward in a ratio of more than 1.5 to 1 patient.

(3) The hospital employs the latest nursing techniques or a standardised nursing system.

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[4] Under the Japanese health insurance system, if doctors give many drugs, injections, and life-prolonging procedures they themselves can benefit financially. Palliative care services and especially psychological support have not been sufficiently covered by insurance, mainly because it was an invisible factor in care (Kashiwagi 1991).

(4) Nurses are on duty throughout the night.

(5) The hospital meets the regulation of medical law in terms of the number of doctors.

(6) The ward has full-time doctors who are in charge of palliative care.

(7) The floor space of the ward is more than 30 square meters, and that of each room is more than 8 square meters per patient.

(8) The ward has an anteroom for the patient's family, a kitchen for the patient's use, a meeting room, and a common room of a certain size.

(9) The ward can contain only single rooms; however, rooms which provide special treatment should be less than 50 % of the total number of the rooms.

(10) There are regulations for admission to and discharge from the ward, and doctors and nurses make the decisions.

(11) Guidance regarding palliative care is available to patients, and both patients and their family are informed about it.

(The Japanese Association of Hospice and Palliative Care Units 1998, cited in American Family Life Assurance Company 2001)

These standards tend to define what a palliative care unit is in terms of hospital facilities, not qualitatively in terms of the kind of care provided to the patients. Consequently, in 1997 the then Japanese Association of Hospice and Palliative Care Units (Hospice Palliative Care Japan at present) issued its Standards of Hospice and Palliative Care Programmes at Institutions (See Appendix 1), which placed more emphasis on the aspect of care. In order to improve and maintain the standard of care at hospice and palliative care units, many training courses for medical professionals based on the Association's standards have been held all over Japan (Takahashi 2002).

2.2. Cancer pain management

In response to the WHO monograph *Cancer Pain Relief* published in 1986 the Ministry of Health, Labour and Welfare in Japan organized a special research team in 1987, which discussed the philosophy of palliative care for two years, and edited national manuals on palliative care for terminally ill cancer patients that included guidelines on cancer pain management (Takeda 2002: 197).

In 1987 the Ministry also organized a special team to research opioid availability and legislative opioid control measures (Takeda 2002: 197). Before then, opioids had not been used very much in Japan, although they are very effective and can control most cancer pain when used properly (Hiraga 1997: 43). One of the reasons for their unpopularity in Japan is explained by misunderstandings about morphine (the mainstay analgesic in cancer pain management) among the general public and even among medical professionals. *The Terminal Care Manual* (Yodogawa Christian Hospital Hospice 1997: 30-31) lists five typical misunderstandings concerning morphine:

(1) Morphine shortens life

(2) Morphine makes patients crazy

(3) Patients develop resistance to morphine and the drug is addictive

(4) Morphine has side effects

(5) Morphine does not work

These beliefs, however, are all clinically proven to be wrong (Hiraga 1997: 47). Such effects mentioned above may appear only if the patient is administered morphine by injection immediately before death (ibid.).

Another factor which influenced the widespread use of morphine was its form—since morphine was not very easy to use. Until 1989, morphine was only available in Japan in powder form, as immediate-release tablets, and as 10-mg ampules for infusion (Takeda 2002: 198). The morphine in powder form did not have a long term effect. Additionally, although the tablet form of morphine powder is easy for the patient to store and carry, it is difficult to take these tablets orally when a dosage becomes large (Matoba 1997: 47).

The arrival of MS Contin, a controlled-release tablet containing morphine, in 1989 changed the whole situation. The new tablets were in available 10, 30 and 60-mg forms, with effect lasting up to 14 hours (Matoba 1997: 47). Although instant effect cannot be expected from MS Contin, patients do not have to take the tablets frequently, and this causes them much less trouble, leading to an increase in the quality of life and enabling patients to control pain at home. Cancer pain is chronic pain, so the long-lasting effect of MS Contin had a powerful influence on the pain control method at that time. It solved many of the problems associated with morphine in powder form. Since the introduction of MS Contin, cancer pain has been relieved more easily, and it has also become 'controllable' for the medical professionals.

Today in Japan, MS Contin is available in other forms, including suppositories, and 10-mg and 50-mg ampules for infusion (Matoba 1997: 48-49). When the patient is unable to tolerate the oral route (e.g., a dosage becomes too much to take orally) a change is normally made to a subcutaneous infusion (Saunders *et al.* 1995: 20). If the patient uses continuous subcutaneous infusion[5], it is possible for him or her to control pain at home. Infusion is also convenient, as it can be included in

IVH (intravenous hyper alimentation) with other drugs such as an anti-emetic or sedatives.

By 1992, the relevant laws and the Japanese pharmacopoeia were revised to improve the accessibility of opioid analgesics to cancer patients after the recommendations made by the aforementioned special research team (Takeda 2002: 197). The annual consumption of morphine for medical purposes has been increasing rapidly, and by 2000 it rose to 1026 kg—almost 100 times more than in 1979 (Takeda 2002: 198)[6].

Since the arrival of MS Contin in 1989, cancer pain has been perceived as controllable by medicine, and a large number of manuals concerning cancer pain management have been published in Japan. For instance, in 1989 the Ministry of Welfare and the Japan Medical Association published the national manual for the care of the terminally ill, which was revised and published under the new title, *Manuals for Palliative Cancer Care* in 2002. In 1992, *The Terminal Care Manual* was edited by Yodogawa Christian Hospital Hospice, and this also has been used as one of the leading textbooks of pain control in Japan, with around 80,000 copies sold since its first publication. Other than these, various other publications on pain control have followed, such as *Control of Cancer Pain* (Dan and Yokota 1993), and *Guideline for Cancer Pain Treatment* (The Japanese Society for Palliative Medicine (ed.) 2000). Moreover, many foreign manuals have been translated into Japanese and published throughout the 1990s.

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[5] A portable battery operated syringe driver or similar device is used and the drugs loaded every 24 hours. This route is used if pain is associated with severe vomiting, dysphagia, or if the patient is semi-conscious (Saunders et al. 1995: 21).

[6] The amount of morphine consumed per capita in Japan is still much lower than that in most developed countries (Takeda 2002: 198).

The use of morphine outside medicine is prohibited by law; therefore, usage requires careful handling, and needs to be controlled strictly by the government. The Ministry of Health, Labour, and Welfare published a number of manuals for medical professionals relating to the supervision of morphine administration. These included: *Manual of Narcotics Management at Medical Institutions, Narcotics and Psychotropic*

Drug Management at Dispensaries, and *Handbook for Narcotics Import and Export Procedures* (all published in 2001). In this manner, the governmental intervention in the hospice and palliative care became inevitable.

The introduction of morphine into hospice and palliative care was innovative. Thanks to it, most cancer pain is now relieved, and the patients' quality of life is much improved. At the same time, however, the introduction of morphine has resulted in the inevitable intervention of medicine and governmental legislation into hospice and palliative care in Japan. This is because morphine is a drug prohibited by law, which needs to be treated under strict management when used as medicine. It can be said that the introduction of morphine has greatly contributed to put hospice and palliative care under the control of the government.

2.3. Education

With the increase in the amount of morphine used for pain control, more medical professionals who are fully aware of the effect of morphine in pain management have become needed. By 1993, however, a survey by the WHO and the Cancer Centre in Saitama (Japan) revealed a lack of knowledge about cancer pain management among Japanese medical professionals. Since then the government and medical, nursing, and pharmaceutical societies have frequently sponsored seminars on

cancer pain management, palliative care, and opioid availability in order to educate all health professionals (Takeda 2002: 198). As mentioned above, a variety of manuals for the care of the terminally ill were published for medical professionals in the 1990s.

Cancer pain relief and palliative care started to be added on syllabuses at medical and nursing schools in 1990. According to Takeda's (2002) survey in 1997–1998, 93% of the 57 responding medical schools teach cancer pain relief and palliative care. All of the existing 37 university nursing schools and 91% of the responding nursing schools at non-university level were also found to have such a course in the syllabus. A study conducted in 2001 reveals that 94% of the 67 responding medical schools and 97% of the 60 responding nursing schools taught palliative care (Kuroko 2003). The number of both medical and nursing schools which include palliative care in the syllabus is increasing. It was also found that more schools called the courses on cancer pain relief 'Palliative Medicine (Care)' in 2001, rather than 'Terminal Care', which was more common in 1995. It is assumed that as a result of the foundation of the Japanese Society for Palliative Medicine, the concept of palliative medicine (care) has been more strongly advocated and has become better established in Japan (Kuroko 2003).

3. Public movement

The hospice movement in Japan was initially started by medical professionals with special interests in terminal care, and the idea was taken up by the government according to the medical professionals' approach. Under this circumstance, how did

the Japanese public become aware of the hospice movement and what was its reaction to it?

Despite the fact that hospice philosophy was introduced to Japan in the 1970s, and that medical and governmental efforts had been made to promote its philosophy since that time, at the beginning of the 1990s treatment given at PCUs and hospices was not much different from that given at other wards at hospitals (T Sugishita: personal communication, June 26, 2002). This fact may have contributed to the lack of public awareness about the hospice movement. In the end, public attention was drawn to the hospice philosophy by the media rather than by medical professionals or the government (T Sugishita: personal communication, June 26, 2002). The most influential incident in this regard was the confession in 1993 of the popular TV personality Masataka Itsumi that he had stomach cancer. The following section illustrates the course that Itsumi took after the first diagnosis. The story is summarized based on books[7] published after his death in December 1993.

3.1. Masataka Itsumi's death

Masataka Itsumi was a TV personality who appeared on many popular TV programmes in Japan. On 18 January 1993, a major tragedy suddenly befell him—cancer was found in his stomach.

Itsumi was diagnosed as having stomach cancer by a surgeon, Dr Maeda, the director of Maeda Clinic. He told Itsumi that his cancer was only at the early stage, so

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[7] *Cancer Redeveloped* (1994) by Masataka Itsumi himself (revised by his wife, Harue Itsumi), *The Crossroad in the 23th year* (1994) by Harue Itsumi, and *Message to Heaven* (1994) by Osamu Miki, the managing director of Miki Production (a TV production company), who supported Itsumi for a long time.

he would be fine once it would be surgically removed.[8] (Dr Maeda, however, later said that the cancer he found had had a diameter of 2 cm which was very advanced. It was also scirrhous gastric cancer which is notorious for its rapid progress.) Itsumi was admitted to hospital on 25 January, and underwent an operation on 4 February.

During the operation, three-fourths of Itsumi's stomach were removed (Itsumi was told that only two-thirds of his stomach were taken out) and Dr Maeda told Itsumi's wife, Harue, that Itsumi's cancer was much more advanced than he had thought, but he still said to her that he had removed all the affected parts, so that Itsumi would be fine. Dr Maeda then started to act in a peculiar fashion. Especially after Itsumi left the hospital on 20 February, Dr Maeda started not to see him as frequently as before. Even though he knew that Itsumi was coming to see him, he was always absent and some other young doctors saw him instead.

After leaving the hospital, Itsumi still believed that his cancer was at the early stage and that all the affected parts had been taken out during the operation. However, he soon felt lump in his stomach. Dr Maeda said to Itsumi that what caused his problems was nothing serious and could easily be cured; however, he did not want to perform an operation, saying that he was shortly taking a summer holiday.[9]

In the end, a deputy director of Maeda Clinic performed Itsumi's second operation. Again, Itsumi was told that the lump was nothing serious and that the cause of it was removed. Yet what his wife Harue heard was totally different. The deputy director told her that the lump was removed, but there was nothing else he could do.

Harue and Mr Miki, the managing director of Miki Production, both told Itsumi that he should seek a second opinion. They finally managed to persuade Itusmi

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[8] At this point, Itsumi's disease was announced as a perforative duodenal ulcer to the public, since cancer was still strongly associated with death and the public might be thrown into an uproar if the truth was announced.

and he decided to see a new doctor, Dr Habu from Tokyo Women's Medical College, who was an authority on cancer operations. On 3 September, Dr Habu consulted Itsumi for the first time. What he said to Itsumi immediately after the consultation was 'Why have you left this until now?' Afterwards, Harue and Mr Miki were called in by Dr Habu and they decided to tell Itsumi the truth.

Dr Habu said to Itsumi, 'The lump in the stomach looks like cancer. If you leave it, you will soon suffer from an intestinal blockage, so it should be taken out before this happens.' Itsumi then asked him, 'Will it be cured if I leave everything to you?' Dr Habu answered, 'We cannot say we can cure it 100 per cent, but we will assemble a team and do our best to remove as many cancer cells as possible. I promise you. Then, God knows.'

Once Itsumi knew the true diagnosis and decided to undergo a major operation to remove the cancer, he made up his mind to give a press conference to announce to the public what he was facing. Harue and Mr Miki did not agree with Itsumi's decision, because the fact that he had cancer could be very stigmatic. However, the press conference held on 6 September 1993 met with a good public response. Those who watched the conference all over Japan cheered Itsumi vigorously. Itsumi, who was known to everyone in Japan as a popular TV personality, suffered from cancer—everyone's enemy. He was also brave enough to announce his true diagnosis to the public, and to undergo a major operation to challenge his cancer, which was a risky undertaking. Itsumi's decision immediately attracted immense public attention. He suddenly became a hero, and everyone expected him to beat the cancer and to miraculously return to TV.

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[9] Itsumi had trusted Dr Maeda from the bottom of his heart; however, Dr Maeda's insincere attitude—he gave his holiday priority over Itsumi's operation—upset him very much.

On 16 September 1993 Itsumi underwent another operation. It was a major operation which lasted for 13 hours. As a result of Dr Habu's effort to eliminate all the affected parts, 3 kgs of the internal organs were removed from Itsumi's body. Despite the scale of the operation, Itsumi improved daily after that, and Dr Habu planned to allow him to stay at home overnight on 23 October.

The plan, however, was cancelled due to severe stomach ache on the appointed day. This was caused by an intestinal blockage. Itsumi was very disappointed, but he was still keen on further curative treatment. He then decided to take anticancer drugs from 8 November. In order to administer these drugs, Dr Habu had to perform another operation on Itsumi who was already totally debilitated. It took the doctor two and a half hours to make a new route for the anticancer drugs to be administered.

The drugs caused Itsumi nausea, thirstiness, and stomatitis, which made it difficult for him to talk. He also lost his appetite. On 15 November, Harue was called by one of the doctors who helped perform Itsumi's operation, and she was told that there was no chance that he would return to society.

The number of tubes connecting Itsumi to intravenous drips and medical devices increased. He was also not allowed to eat anything. His deterioration accelerated further, and he died on 25 December 1993.

3.2. Influence of Itsumi's death on the public

Itsumi's condition and the treatments he received were fully reported to the public every day. Everyone believed that he would return to normal life, since the most famous doctors in Japan performed the operations. His death was therefore very shocking to the public. In the following year, several books were published to reflect on Itsumi's death, revealing the dreadful last days before his death (see footnote 7 in

this chapter). These books commonly highlighted three points. Firstly, that Itsumi and his family were not told the true diagnosis. Dr Maeda, for example, made his true diagnosis (i.e., that Itsumi had scirrhous gastric cancer which was already at a relatively late stage when it was detected) known to the deceased's family and the public only after Itsumi's death. Secondly, that famous doctors announced they would cure Itsumi's cancer although the attempt was medically senseless. Thirdly, that the operations which Itsumi underwent not only declined his quality of life but also hastened his death. What became clear to the public was that Itsumi could not control his own death and his own way of dying, firstly, because he was not told the truth, and, secondly, because he trusted his doctors too much to make his own decisions.

Itsumi's death threw doubt on the conventional treatment of cancer patients (i.e., not telling the truth to the patient and giving too much curative treatment). It inevitably made the public think more about the dying process and how to lead the last days of one's life as comfortably as possible. The public became aware of the advantages in being told the truth and in being able to make one's own decisions. Consequently, public attention turned to hospice and palliative care.

Following the books on Itsumi's death, a number of books giving an account of cancer treatment to the public were published in Japan. The most influential of these was *Patients, Don't Fight Cancer* published in 1996 by Makoto Kondō, a doctor from Keiō University. This book became a best-seller and sold 450,000 copies. It was a very sensational book, as it exploded the established theory on cancer treatment. For example, Kondō argues that cancer checkups are not reliable; early detection of cancer does not help patients; and that anticancer drugs do not work. The book aroused much criticism by other doctors, and a number of books both for and against Kondo's arguments were soon published; for example, *Patients, Fight Cancer!* by

Nagano (1997), *Please Don't Die From Cancer Without Fighting It* by Hiraiwa (1997), *Patients, Don't Fight 'Death'* by Nakahara and Fuke (1997), and *Informed Consent Does Not Save Patients* by Natori (1998). The authors of all these books are medical doctors who specialize in cancer treatment. It can be said that Itsumi's death made both medical professionals and the public rethink the state of cancer treatment at that time. Given the enormous increase in the interest of the public in cancer treatment, Itsumi's death also provided a good opportunity for medical doctors to tell the public everything about cancer treatment and to explain the real situation to them. As a result, the public was exposed to even more information on cancer, which increased not only their knowledge but also their concern about life and death in general.

Itusmi's case reinforces the general principle of social organization that 'the mass media plays a decisive role in the formation of public opinion in society' (Noelle-Neumann 1999: 52). In other words, the media acts as an agent of social change in modern society dominated by the media. A commonplace occurrence amongst the public suddenly becomes a critical problem when interpreted and framed by the media and by celebrities through the media. Even before Itsumi's case started to be reported in 1993, there had been many cancer patients, who may have died in an unfortunate way, and many interested medical professionals had been promoting hospice philosophy in Japan. However, it is mainly after Itsumi's incident that the public gaze focused on hospices and PCUs, and more generally on the process of dying. The idea of hospice did not infiltrate into the public until it was reported via the mass media. The events surrounding Itsumi's death were not just a one-off. Taken up by the media, they served to stimulate public awareness and influence public opinion.

3.3. Other influences

In the early 1990s, when Itsumi's incident occurred, the Japanese social condition was rather unstable; Japan was facing the collapse of the 'bubble economy'. During the bubble economy, the heart of the public tended to be set on moneymaking and the idea of a fruitful life, with the family, for example, was almost forgotten (The Mainichi 2001). People looked upon the immediate future and profit as important. When the economic collapse started, however, the Japanese public started to place more value on nature, culture, and the quality of life (The Ministry of Construction 1998). One might say that public attention has shifted from the quantity of money to the quality of life.

Under these circumstances, Itsumi's ordeal under the medical treatment described in the previous section shocked the public. Itsumi spent a great deal of money in attempting to beat his cancer, but he was unable to spend his remaining life as he wanted to, and went through unreasonable suffering which degraded the quality of his remaining life[10]. Consequently, the public have threw doubt on cancer care with too much medical intervention and put more emphasis on exploring how to spend one's life after diagnosis in a more fruitful way. The merit in truth-telling was also reconsidered, and the statistics show the increase in the rate of the public who express a desire to be told if they develop incurable cancer; 64 % of healthy adults in 1990 (Mainichi Shinbunsha, cited in Morioka 1994: 147) increased to 72.6 % in 1998 (Minister's Secretariat. The Ministry of Health, Labour and Welfare 2000: 84).

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[10] Kondō (2001) later had an interview with Harue, and said that the last operation which Itsumi underwent was medically senseless, and that he could have lived for another year without much pain if he had not gone through the operation. This interview was first published in 1997.

The appearance of AIDS in the 1980s may also have had an influence on Japanese people's attitudes towards cancer. This event may have made it easier than before for the Japanese public to talk about cancer in their daily life, as the stigma associated with cancer shifted to AIDS (T Sugishita: personal communication, June 26, 2002). AIDS is, in one sense, like cancer, because its association with death is so powerful. Additionally, both cancer and AIDS are sometimes understood as the fault of someone who has indulged in 'unsafe' behaviour. For example, drinking and smoking are associated with esophagus and lung cancer respectively. The unsafe habits associated with cancer are largely viewed as the price one pays for excesses of diet and 'life-style' resulting from a weak will, lack of prudence, or addiction to legal chemicals (Sontag 1998: 25). The unsafe behaviour which causes AIDS is, on the contrary, judged to be more than just weakness. It is understood as a disease of delinquency (i.e., addictions to illegal chemicals and sharing contaminated needles) and of sexual excess (Sontag 1998: 26). Especially at the beginning of the AIDS epidemic, it was believed that heterosexual transmission was very rare and unlikely; thus AIDS was also understood as a disease of perversity (Sontag 1998: 26). These aspects of AIDS combined to make it a new symbol of stigma in Japan.

At the same time, the number of deaths caused by cancer was increasing, and in the early 1980s cancer became the most common cause of death in Japan (Health and Welfare Statistics Association 2001). During this period, several Japanese AIDS patients were found. In 1985, the first Japanese AIDS patient was reported (Miyazaki 2000). This was a homosexual Japanese male living in the United States. Then the famous 'Kobe Panic' followed. On 17 January 1987, the then Ministry of Health and Welfare announced that the first Japanese female AIDS patient was found in Kobe (Kimura 2000). It was also reported that she was a prostitute, which threw a number

of men into a panic[11]. Since then, AIDS has been recognized as a disease which affects anyone regardless of nationality and sex, and the year 1987 was determined to be the first year of the AIDS era in Japan (Kimura 2000).

Through these events, the Japanese public was exposed to the menace of another incurable disease. As explained before, AIDS carries more unfavourable connotations than cancer, and it is incurable. For these reasons, it can be said that since the 1980s the cancer stigma has been replaced by AIDS, and cancer has become a disease with little taboo which can be talked about more openly. This has encouraged the public to discuss cancer more frankly with medical professionals, which has led, in turn, to an increase in the number of people who would prefer to know the true diagnosis rather than to be lied to.

4. Summary

In this chapter I have presented an overview of the hospice movement in Japan (see Table 3). Japanese hospices and PCUs were firstly established by interested medical professionals, and later enhanced with the assistance of the government. The public recognition of hospice and PCUs grew rather slowly, and they may not have attracted considerable public attention until when Itsumi's difficult death was intensely reported to the public, followed by many books on cancer treatment written by doctors for the public. Itsumi's death may have thrown doubt on the conventional cure-oriented cancer care at hospitals, and taught the public that one cannot die in his or her own way or die with dignity unless he or she is fully aware of the truth and given the chance to make a decision on treatment. This trend, in other words, shows

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[11] Between 17th and 20th January 1987, 1,092 people took an AIDS test, and 3,195 visited health centres to discuss

Year	Medical professionals	The Government	The Public
1971			Japanese translation of *On Death and Dying* published.
1973	First hospice and palliative care service in Japan, Organized Care of the Dying Person (OCDP), established by Tetsuo Kashiwagi.		
1977	Japanese Association of Clinical Research on Death and Dying established.		
1977	Sōichi Suzuki visits St Christopher's Hospice in London. Hospice is introduced in newspapers.		
1977	Percentage of deaths that took place in hospital overtakes that of home deaths.		
1981	Malignant neoplasms become first cause of death in Japan.		
1981	First hospice in Japan, Seirei Hospice (Shizuoka), established.		
1984	Yodogawa Christian Hospital opens a hospice ward (Osaka).		
1985			*The Book to Help You Understand Prescribed Medicine* published. First AIDS patient in Japan reported. First Japanese female AIDS patient found in Kobe ('Kobe Panic')
1987		Special team to research opioid availability and legislative opioid control measures organized.	

possible AIDS infection (Ienishi 1996).

1989		Arrival of MS Contin National manual for palliative cancer care published by the Ministry of Welfare and the Japan Medical Association.	
1990		Medical insurance benefits from the Government start to be provided for hospices. Standards for hospice and palliative care units established.	Collapse of 'bubble economy' in the early 1990s. *Dying in a Japanese Hospital* published by Fumio Yamazaki.
1991	The Japanese Association of Hospice and Palliative Care organized.		
1992	*The Terminal Care Manual* published by Yodogawa Christian Hospital Hospice.		
1993			Masataka Itsumi confesses he has stomach cancer in January. Itsumi dies in December. Yamazaki's best-seller book *Dying in a Japanese Hospital* made into a film.
1994			Books regarding Itsumi's death are published.
1996	Japanese Society for Palliative Medicine established.		A number of books giving an account of cancer treatment to the public are published. *Patients, Don't Fight Cancer*
1997			*Patients, Fight Cancer! Please Don't Die From Cancer Without Fighting it*
1998			*Informed Consent Does not Save Patients*
2000		*Guideline for Cancer Pain Treatment* published by the Japanese Society Palliative Medicine.	

2001		Number of manuals for medical professionals relating to the supervision of morphine administration published by the Ministry of Health, Labour, and Welfare.	
2004	Japanese Association of Hospice and Palliative Care changes its name to Hospice Palliative Care Japan in July.		

Table 2. Summary of the hospice movement in Japan

that the public has become more interested in how to die a 'good death' than before, and has started to rethink the conventional cure-oriented cancer care. In short, the public has started to seek 'anti-institutionalized death'.

While public interest was moving towards 'anti-institutionalized death', hospice and palliative care in Japan was growing more institutionalized for various reasons. In order to obtain financial assistance from the government, hospices and PCUs were required to meet the standards laid out by the government. The usage of morphine has also inevitably allowed the government to intervene in hospice and palliative care. Additionally, many manuals concerning hospice care and effective morphine usage have been published in Japan. Thus, not only the hospice physical facility but also the care and treatment available there have been standardized all over Japan. This not only means that anyone in Japan can receive hospice care to a certain quality wherever they are, but also that care has become so standardized that the choices of patients are considerably constrained. It requires little imagination to argue that the standardization of hospice and palliative care has also standardized the ideology of a good death within the institutions. This trend tends to put death and

dying under what Hart *et al.* call 'a new form of social control' (1998: 75), and 'the social management of dying and death' (ibid) within the hospice movement is its result.

Another significant aspect of the hospice movement in Japan is the development of palliative medicine. As explained in chapter 1, the terms hospice care, terminal care, palliative care and palliative medicine all refer to the same thing in Japan at present. Strictly speaking, however, palliative medicine is, 'a special field of *medicine* which aims towards *positive* care' (Kashiwagi 1997: 15; emphasis added), yet in the case of palliative medicine, the positive direction does not go towards life prolongation, but towards pain relief (ibid.). In other words, palliative medicine also employs the most advanced high-technology, just as any other medical disciplines.

Pain relief plays a very important part within hospice care in order to improve the patients' quality of life; however, a growing interest in palliative medicine seems to have made people forget the original purpose of hospice philosophy—*care* for the dying. For a long time, care for the dying has been seen as the defeat of medicine, because death should be avoided by the use of medicine. However, palliative medicine has made it possible to give a *positive* connotation to the role of medicine at hospices and PCUs. It makes use of modern technology to relieve cancer pain, which provides a visible effect, unlike other aspects of hospice care, such as care for psychological pain. It could be argued that palliative medicine was developed in order for medical professionals to feel comfortable and satisfied at the occasion of a patient's death. In other words, doctors and carers do not need to feel powerless and helpless when they have made full use of medical technology under the pretext of pain relief.

The Japanese psychiatrist Hirayama (2000) points out that:

> The word 'palliative' originally implies a meaning of mantling or masking. In other words, palliative medicine masks patients' pain, suffering and agony by using morphine or sedatives. In this sense, it is notable that palliative medicine tries to conceal pain, agony, and fear of death in the same way as life-prolongation and first-aid medicine used to do[12].
>
> (Hirayama 2000: 59)

Hirayama concludes that life-prolongation and first-aid medicine, with the aim of the 'medicalization of death', and palliative medicine, with the aim of the 'humanization of death', are both fully engaged with modern technology, and share a common feature; that is to say, both try to conceal death and emphasize 'life'. Why does modern medicine always conceal death? Hirayama argues that it is because people try to overcome fear and anxiety associated with death by using the power of science.

The hospice movement was commenced voluntarily by some interested medical professionals in Japan with the aim of promoting more humane care for the dying. However, Japanese hospice and palliative care has now become more institutionalized and, in serving the needs of the staff and institutional resources, it has become a method of reinforcing the hospice's ideology of a good death (see chapter 7). As this chapter has outlined, this trend can also be explained in terms of external elements: the standardization of care and treatment by the government and the organizations established by the leading hospice doctors. Death is also concealed by medicine—as with the development of palliative medicine, which, again, has been established by leading hospice doctors. The hospice philosophy promoting humane

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[12] Similarly, Lawton (1998) points out that 'the actual word "palliative" is derived from the Latin noun pallium, meaning "cloak"' (139). To palliate means, therefore, 'to cover with or as with a cloak ... to hide, conceal, disguise' (Scott 1994: 37, cited in Lawton 1998: 139).

care and encouraging the patient to accept death as a normal event in one's life has consequently turned out to create another form of institutional and medicalized death in Japan.

Chapter 9: Conclusion

Patterns of disease and causes of death in Japan have changed since the beginning of the 1950s (see chapter 8). The number of people who die from life style diseases (e.g., cancer), which are more chronic and possibly need long-term hospitalization, increases every year. In the 1970s, the hospice philosophy was introduced to Japan from the West, and since then, the hospice and palliative care has infiltrated into Japanese society. How has this change in trend of death and dying affected death culture in contemporary Japanese society? In this thesis I have attempted to explore this question by examining the changes of funeral practices and dying process in Japan from two perspectives: the anthropology of death and dying, and the ethnography of Japan.

From a perspective of anthropology of death and dying, I have used van Gennep's theory of rites of passage (1960) in order to analyze the dying process. Within this context, I have placed the dying process as the transitional period between the separation (entering the PCU) and the incorporation stages (funeral rituals) (see chapter 3).

The new way of viewing the dying process provides a means to explain aspects of the modern funerals which function without a notion of 'journey' and lack a concept of death pollution. In contemporary Japan, it is the dying process that plays

the role of 'journey' from life to death, and during this period many medical routines are conducted in order to try to control and remove the uncertainty, dread, and fear associated with death and dying, just as people in traditional Japan conducted funeral rituals for the same objectives.

I have also analyzed the period of patients' being at PCUs as a liminal period, and examined how the nature of liminality can explain some aspects of patients' situation at a PCU. For instance, I have seen patients as 'liminal *personae*' who are, as defined by Turner (1969), structurally ambiguous and polluting, and are totally under the control of the instructors of the ritual. They form a *communitas,* which consists of equal individuals submitting together to the general authority of the ritual elders. Indeed, at PCUs, patients are structurally ambiguous entities; they are neither alive nor dead. They are also subjects of dread, as imminent death brings uncertainty and discomfort amongst the carers. Patients are physically weak and dependent, which makes them prone to being under the carers' control. Their pain and symptoms are also controlled by medicine. In the hospice setting, the position of patients is analogous to that of ritual subjects during a liminal period as defined by Turner. However, the hospice philosophy and the hospice setting have attempted to put the patients in an unusual situation within the context of liminality. Namely, the hospice philosophy encourages patients to have autonomy and aims to provide patient-centred care. In other words, in the hospice setting, it is the ritual subjects (the patients) who are expected to control their body and their dying process, not the ritual instructors (the PCU staff). This is the ideal; however, in this thesis, I have shown that the ideal of patient-centred care is not attained in reality: many patients fail to have autonomous attitudes toward dying, and experience social death before they

physically die, instead of controlling their dying process. The anthropological framework of liminality provides a means to explain why this is the case.

I have also discussed ritualistic aspects of medical routines (chapter 7) and demonstrated how medical routines contribute to the smooth running of the PCU as an institution rather than contribute to patient-centred care: hospice/palliative care has become routinized because routines are beneficial for the staff and the institution. The standardization of care by the government has also encouraged the routinization of care (chapter 8). Hospices and PCUs, which were initially developed in order to provide humane care, have become places which provide a new form of institutionalized death, and consequently constrain the patients' dying patterns (chapter 7). Institutionalization and medicalization of hospice care is not only a problem in Japan, but also in the West (see Walter 1994; McNamara 1994; 2001; Lawton 1998; 2000; Clark 2002). This fact shows that the reason for the difficulty in practicing the hospice philosophy cannot be simply explained by cultural or religious differences between Japan and the West.

My research also shows that in contemporary Japan death is hard to be accepted as it is. Death is sad and dreadful, and the dying are subjects of dread. In order for the dying to be accepted by their surroundings, death and dying are reinterpreted as a meaningful experience. By explaining the dying process as a transitional period using van Gennep's framework of rites of passage, I have highlighted that during the dying process, death is transformed into a positive experience so that the dying can still live as a socially meaningful existence. The dying process at the PCU is not only a transitional process from life to death for the dying but also a process where death is made good and meaningful.

This thesis can also be read in the context of Japanese ethnographic studies on health, illness and death. Traditionally in Japan, death which leads to the disruption of *ie* (a family household) was thought most dreadful. Death which causes a deep attachment of the soul to this world should also be avoided (e.g., death by accident) as the soul was thought to bring misfortune to the living. As a good death, dying '*isagi-yoku*' (without regrets) was highly valued. In reality, however, it was found to be difficult to die '*isagi-yoku*', because it requires great strength of spirit. The ideal Japanese death would be *rōsui* (a gradual decline leading to death in old age) or to die *pokkuri* (sudden death) so that an individual does not impose heavy burdens on the family when dying. This thesis has explored how these traditional concepts of ideal death have changed in the face of medical advances and changes in pathologies (most notably the appearance of life style diseases as major causes of death in Japan) which have changed the process of dying; for example, dying of cancer has become a challenge to both *rōsui* and *pokkuri*, as it is often neither sudden nor pain-free.

Given this situation, it is natural that the Japanese public would be attracted by the hospice philosophy, and it is interesting from an anthropological point of view to see how this Western-born philosophy has been adopted by the Japanese. For example, my field observation shows that the hospice ideology of good death is interpreted by the Japanese public as dying peacefully (*yasuraka ni*) or naturally (*shizen ni*) rather than as 'living as actively as until the end' as the hospice philosophy originally proposes. It looks like the Japanese public prefers to leave their illness to take its own course rather than to seek how to 'live' until the end.

This Japanese attitude toward the dying process reflects Japanese concepts of health and illness. Although Japanese patients seem to have a passive attitude toward the dying process, they are in fact very keen to 'control' their illness and to manage

their body condition using their *tairyoku* (physical power) (see chapter 4). The idea of *tairyoku* is, however, not scientific enough for the PCU staff, and the patients' belief in *tairyoku* sometimes interferes with the medical treatment as shown in the case studies in chapter 4. Moreover, those who seriously believe in *tairyoku* are more likely to wish to stay at the PCU even when the staff suggest to them that they go home so that they can spend fruitful time with their family at home before they die. Those patients try to rebuild their *tairyoku* at the PCU in order to cure cancer while their pain and symptoms are well managed. This kind of patients' behaviour is contrary to the hospice philosophy, and it also disappoints the PCU staff. More importantly, this kind of patient is not regarded as a good patient by the PCU staff, and consequently their death is not considered a 'good death'.

The hospice philosophy was introduced to Japan to meet a demand for patient-centred care and uninstitutional death. However, hospice and palliative care in Japan has grown more standardized and institutionalised (see chapter 8). The ideology of good death has also been standardized in favour of PCUs as institutions, and this makes it difficult to provide patient-centred care. In contemporary Japan, death and dying are under a new form of social control, which results in institutionalized good death. There is also a gap between the hospice ideology of good death and how the lay Japanese public wishes to die. I believe that my thesis has demonstrated why this has happened from the view points of both anthropology and Japanese ethnography.

There are some limitations in this research which should be addressed as a means for improving further studies. An important limitation is that I examined only patients at PCUs in order to investigate death and dying in contemporary Japan. The reason for this is firstly because the increasing number of deaths caused by cancer means that a large number of Japanese people go through a long process of dying

these days and it is ideal to observe patients at PCUs as representatives of such people. Secondly, the increasing number of hospice and PCUs reflects the increasing demands of Japanese public for special care for the dying. I believe that examining patients and their families at PCUs clarifies the most recent ideas and attitudes towards medicine, illness, death, and dying held by contemporary Japanese people. However, there are also many other kinds of death, such as murder, death by accident, suicide, and sudden death which do not involve a long process of dying, and would be categorized as 'unusual/abnormal death' in Japan. It would be interesting to investigate how these types of death are treated in contemporary Japan and how Japanese people try to accept them without the transitional period where death is made meaningful. Such a study would complement what this thesis has provided and would also shed a new light on the concept of 'good death' by providing the reverse concept.

I also deliberately did not include issues of religion in regard to palliative care, because I thought this would take attention away from the main object of study by involving spiritual, philosophical, and historical factors and they are too complex to treat in the same study.

Moreover, not all Japanese cancer patients receive treatment at hospice or PCU. Due to the small number of such institutions compared to the number of deaths by cancer, many still die at institutions other than PCUs or hospices[1], and there are also some patients who receive treatment at home. Home care is a particularly interesting issue, as it is a new form of hospice/palliative care in Japan. When applying Turner's ideas of the liminal period to home care, there are some aspects that

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[1] In 2003, approximately 310,000 people died of cancer in Japan (The Ministry of Health, Labour and Welfare 2005). The number of hospices and PCUs in the same year was 120 with 2287 beds (The Japanese Association of Hospice and Palliative Care Units 2003).

contradict his theory. Although the instructor of the ritual (i.e., medical treatment) is still a medical professional and the ritual subject is a patient in the setting of home care, the patient does not form a *communitas* with other patients, and is not secluded from the place he or she lives in. It will be interesting to include this new type of palliative care into future research, as it may provide us with a new insight of the liminal/transitional period.

Finally, another interesting aspect to consider for future research is the recent changes in the Japanese funeral industry. Some people find that the commercialized funeral has no meaningful substance but it is only form, and they hold a more individualized funeral ceremony such as the family funeral (*kazokusō*) (Breen 2004). In my future research I would like to take account of the role of family funeral as part of the changing trend in death and dying.

Appendix

Japanese Association of Hospice and Palliative Care Units Standards of Hospice and Palliative Care Programs at Institutions

January 19, 1997

These standards set forth guidelines for mutual cooperation between persons receiving hospice/palliative care and care providers at a hospice/palliative care unit approved by the Ministry of Health and Welfare or a prefectural governor according to "Regulation of Palliative Care Units".

Standards of hospice/palliative care at institutions licensed by the Japanese government

At institutions providing hospice/palliative care program, staff must first comply with applicable local and national laws and regulations governing the organization。

Patients and their family members

1. Patients with malignant neoplasm or AIDS referred by a physician after it has been established that there is no hope for cure.
2. The patient and/or family members requests his or her admission to a hospice ward.
3. On admission, it is desirable that the patient understand the name and condition of his or her disease. At the patient's request, an appropriate explanation will be given.

4. The staff will not discriminate against patients based on the patient's economic, social, or religious status. It must be acknowledged that the patient may live alone, have low income, or believe in a particular religion.

Care program

1. A care program will be provided at the request of the patient/family members.
2. Accurate and current records on the care and treatment offered to all patients/families will be maintained.
3. Informed consent concerning symptom control and care is an essential requirement.
4. A care program for family members and loved ones should be available before the patient's death.

Palliation of pain and other symptom

1. Every effort will be made to control pain and other burdensome symptoms with appropriate treatments.
2. Symptom control will be carried out under mutual agreement, assessing the physical, psychological, and social needs of both patients and family members.
3. Pain control and palliation of symptoms will be supplied referring to standardized books listed at the end of this document.

Care team workers

1. The care team consists of such professionals as physicians, nurses, social workers, and volunteers, positioning patients/family members at the center of the team.
2. Team members respect each other's roles, exchange views on an equal footing, provide mutual supports, and hold the concept and the goal of hospice/palliative care in common.
3. The care team will hold regular training programs and audits to help team members become increasingly effective.

Volunteers

1. A volunteer will be considered one of the team members and an essential care provider.
2. Volunteers take part in the care team of their own accord, and will be expected to know their role on the team and to take reasonable responsibility for their own activities.

Bereavement services

1. Bereavement services will be available from the time the patient begins medical treatment to support his or her family members and other loved ones.
2. When family members or other loved ones are in morbid grief, sufficient consultations by specialists will be available.

Quality assurance and activity assessment

1. The treatment and care given to patient and family members will be

reviewed and assessed.

2. The direction of the care team and the overall care program will be reevaluated.
3. The assessment and reevaluation will in principle be the responsibility of each institution.
4. A special committee consisting of several members of this Association and additional external representatives will be established. The committee will be able to advise any institution based on an examination of its Quality Assurance and Activity Assessment.

Revision of these standards and establishment of a special committee

1. These standards may be revised in accordance with the rules of this Association.
2. The details of the Committee for Quality Assurance and Activity Assessment will be laid down separately.

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