

Inoue, Setsuko (2014) *Promoting truth-telling (the concept and its practice) with effective communication in medical settings: with particular focus on end of life care in Japan*. PhD thesis.

<http://theses.gla.ac.uk/5180/>

Copyright and moral rights for this thesis are retained by the author

A copy can be downloaded for personal non-commercial research or study, without prior permission or charge

This thesis cannot be reproduced or quoted extensively from without first obtaining permission in writing from the Author

The content must not be changed in any way or sold commercially in any format or medium without the formal permission of the Author

When referring to this work, full bibliographic details including the author, title, awarding institution and date of the thesis must be given

**Promoting Truth-telling (the concept and its practice)  
with Effective Communication in Medical Settings:  
with Particular Focus on End of Life Care in Japan**

**Setsuko Inoue**

**A thesis submitted to the University of Glasgow  
for the degree of Doctor of Philosophy in the Department of  
Theology and Religious Studies.**

**Feb. 2014**

**©Setsuko Inoue 2014**

## Contents

Contents .....	i
Abstract .....	v
Introduction .....	1
 <b>Chapter One</b>	
<b>Truth-telling in Medical Practice and its Research in the West .....</b>	<b>7</b>
Abstract to Chapter One .....	7
1. The influence of the Hippocratic Oath and the Bible on medical practice in the West ..	7
2. Historical approaches to patient care and truth-telling in medical practice in the West ..	9
3. A historical survey of hospital-based research into truth-telling concerning mainly cancer from the 1920s to the 1970s .....	19
4. The Dignity of the human being and patient autonomy emerge as core values to affect truth-telling in medical practice .....	28
Conclusion to Chapter One .....	30
 <b>Chapter Two</b>	
<b>Tracing the growing emphasis on truth-telling and patient-centered medical care in the West .....</b>	<b>33</b>
Abstract to Chapter Two .....	33
1. The effect of hospice & palliative medicine on truth-telling: the concept & its practice	34
2. Change of truth-telling and its research to hearing patient's wishes and concerns .....	37
2.1 Patient's wishes and concerns on truth-telling of diagnosis .....	41
2.2 Patient's wishes and concerns on truth-telling of treatment and its options .....	49
2.3 Patient's wishes and concerns on truth-telling of prognosis .....	52
2.4 Not telling truth of medical error, interaction problems, and etc. ....	56
2.4.1 The sincere statement that Physicians say, "I'm sorry", is anticipated by patients ..	57
2.4.2 Physicians' telling a lie and/or deception .....	58
2.4.3 Withholding truth and/or information from the psychotic patient .....	59
2.4.4 Physician's telling a lie to patient at the request of the family .....	60
2.4.5 What patients wonder at the end of life .....	62
2.4.6 Hope vs. truth-telling to be pondered before an interaction with patient at the end of life .....	64
2.4.7 How physicians should change for patients at the end of life .....	64
2.5 Interdisciplinary Team needed for Truth-telling: the concept and its practice .....	66
2.6 Patient centered Truth-telling practice and its Research expected in the 21 <sup>st</sup> century ..	68
Conclusion to Chapter Two .....	70

## Chapter Three

<b>Japanese Tradition and its Impact on current medical practice in Japan .....</b>	<b>72</b>
Abstract to Chapter Three .....	72
<b>1. Japanese traditional values .....</b>	<b>73</b>
1.1 The meaning of “human being” .....	73
1.2 The absence of individualism in Japan .....	74
1.3 The nature of Japanese language and communication .....	77
1.4 Japan as a hierarchical society .....	78
1.5 “Giri Ninjyo” as the core tradition of Japaneseness on how to treat others in daily life .....	78
1.6 Japanese Household (“Ie”): the vital tradition with Insider vs. Outsider .....	79
1.7 The family (“Kazoku”) in Japanese society .....	80
1.8 The adoption of children to continue the family .....	80
1.9 Family care of the elderly .....	81
1.10 Gender and conventional gender roles in Japan .....	82
1.11 The problem of importing abstract concepts to Japan .....	84
<b>2. Characteristics of Japanese medical practice: past and present .....</b>	<b>87</b>
2.1 The influences of foreign countries on Japanese medicine and its practice .....	87
2.2 Bioethics in Japan .....	89
2.3 Patient autonomy in Japan .....	90
2.4 Japan: the Absence of patient’s autonomy with his/her own decision made .....	92
2.5 The family and patient autonomy .....	93
2.6 The tradition of paternalism in Japan .....	96
2.7 Japanese medical practice of patients at the end of life: Past vs. Present .....	99
<b>3. Traditional attitudes vs. present tendency on death and dying in Japan .....</b>	<b>100</b>
3.1 Traditional Japanese perspectives: death is always with life .....	100
3.2 Large spiritual vacuum left among Japanese, because Japan lost in World War II ...	102
3.3 For here-and-now driven Japanese, thinking of end-of-life is almost impossible!!! ...	102
3.4 Death is a normal part of life with which physicians are expected to help .....	103
3.5 Dying vs. life prolonging machine: Which would be the best for patient autonomy?	104
<b>4. Palliative medicine and the hospice movement in Japan for patients at the end of life .....</b>	<b>104</b>
<b>5. Japan Society for Dying with Dignity: Japanese Patient Autonomy duly acted out ...</b>	<b>109</b>
5.1 Influence of the Japan Society for Dying with Dignity on Japanese society .....	111
5.2 The Characteristics of the Japan Society for Dying with Dignity .....	113
Conclusion to Chapter Three .....	115

## **Chapter Four**

<b>Research into truth-telling and treatment practices in end of life care in Japan ....</b>	<b>117</b>
Abstract to Chapter Four .....	117
<b>1. Research, studies, and surveys on truth-telling and treatment at the end of life in Japan</b>	<b>118</b>
1.1 Research, studies, and surveys of truth-telling to cancer patients .....	120
1.2 Whether physicians divulge truth of diagnoses to their patients .....	121
1.3 The influence of the Japanese family on truth-telling in the medical setting .....	123
1.4 Telling truth of Prognosis to patients and their families .....	127
1.5 The case of Dr. Yamazaki's patient .....	129
<b>2. Good practice regarding truth-telling in medical settings in Japan .....</b>	<b>136</b>
<b>3. The practice of withholding and withdrawing life sustaining treatment in Japan .....</b>	<b>142</b>
<b>4. Lawsuits in Japan on patients at the end of life .....</b>	<b>145</b>
4.1 Euthanasia driven “accidents” at Tokai University Hospital and Kyohoku Hospital ...	146
4.2 Truth-telling driven mal-practices claimed by the families of the patients .....	148
<b>5. Japanese Guidelines on the treatment of patients at the end of life .....</b>	<b>153</b>
<b>6. Home-based care of terminally ill patients .....</b>	<b>153</b>
<b>7. Research into the role of medical staff in caring for patients at the end of life .....</b>	<b>154</b>
Conclusion to Chapter Four .....	158

## **Chapter Five**

<b>Developing trust and critical &amp; creative contemplation (“CCC”) for truth-telling medical practice .....</b>	<b>161</b>
Abstract to Chapter Five .....	161
<b>1. Identifying the blockages to effective communication in medical settings .....</b>	<b>161</b>
1.1 Barriers to effective communication in the physician-patient relationship .....	161
1.2 The historical emergence of the value of truth-telling .....	163
1.3 Medical paternalism .....	164
1.4 How best to respect human dignity and difference? .....	164
1.5 Human frailty: denial and avoidance strategies .....	165
1.6 The influence of cultural values and traditions .....	165
<b>2. Overcoming traditional barriers and building bridges to effective communication ...</b>	<b>166</b>
2.1 Trust in the service of truth-telling (the concept and its practice) .....	167
2.2 Glaser and Strauss's USA-based research findings of the 1960s .....	171

<b>3. Critical and Creative Contemplation (“CCC”): A proposal to develop insight and interaction between (1) patient and/or family and (2) physician and/or medical team ..</b>	<b>174</b>
<b>3.1 Applying CCC to the providers and recipients of medical care .....</b>	<b>178</b>
<b>3.1.1 CCC applied to the patient at the end of life .....</b>	<b>178</b>
<b>3.1.1.1 CCC in relation to the psychology of the patient at the end of life .....</b>	<b>182</b>
<b>3.1.2 CCC applied to the family of the patient .....</b>	<b>183</b>
<b>3.1.3 CCC applied to the physician or medical team in regard to the patient facing death</b>	<b>186</b>
<b>3.1.3.1 CCC and the virtuous physician .....</b>	<b>188</b>
<b>3.1.4 CCC as applied to the Chaplain to the patient and/or family at the end of life ...</b>	<b>191</b>
<b>3.2 How does CCC relate to medical practice in Japan? .....</b>	<b>195</b>
<b>3.3 How is death, in its individual &amp; universal meanings, grasped through CCC? .....</b>	<b>198</b>
<b>Conclusion to Chapter Five .....</b>	<b>199</b>
 A proposed conclusion within the limits of the present work .....	 201
 Bibliography .....	 204

## **Abstract**

This thesis deals with the concept and practice of truth-telling in medical settings. In particular, it analyses the way in which truth-telling is enacted in the context of end of life care in Japan. The thesis addresses not only the content of what is communicated in encounters between physicians and medical personnel with patients and their family carers (next of kin), it also discusses the way in which information concerning diagnosis, treatment, and prognosis is communicated. That is to say, in the quality and integrity of the encounter.

The thesis offers a literature survey of research studies that address truth-telling in medical settings in the USA, the UK, and in Japan, offering a comprehensive survey of studies written in English and Japanese. It investigates the history of the concept and practice of truth-telling in medicine from the turn of the twentieth-century to the present day, and it connects this history to the developing field of medical ethics. Over the course of this history one can identify a shift – especially in the West – away from medical paternalism towards patient-centered medical care, in which patient autonomy and self-determination are highly valued. This has influenced the understanding and practice of truth-telling in medicine.

Japan, however, has preserved certain cultural values, traditions, and conventions that affect medical practice. The thesis analyses the effect of these behavioural norms on truth-telling practices in end of life care in Japan. It is argued that the hierarchical society, strong family structure, paternalistic culture, and conversational etiquette of Japan tend to stymie effective communication and limit truth-telling concerning diagnosis, treatment, and prognosis in medical settings.

In light of the findings of the literature survey, the thesis proposes some concrete ways to promote truth-telling and effective communication in medical settings, including through the building of trust between interlocutors and through the reflective praxis of critical and creative contemplation.

# **Promoting Truth-telling (the concept and its practice) with Effective Communication in Medical Settings: with Particular Focus on End of Life Care in Japan**

## **Introduction**

This thesis is related to the promotion of truth-telling and effective communication in medical settings and, in particular, on end of life care in Japan. While the value and importance of truth-telling in medicine are widely accepted across the globe in medical settings, patients are not always told the full truth about their medical condition. This thesis looks at the history of medical practice in truth-telling, and examines the reasons why patients have not always learned the full facts about the diagnosis, treatment, and prognosis of their illness.

In simple terms, the research question of the thesis is: “What do physicians tell to patients and/or the family of patients at the end of life with regard to the truth of diagnosis, treatment, and prognosis of disease?”. In order to better understand the various factors that influence the ways that physicians interact with their patients regarding disease and treatment options at the end of life, I explore the history of medical practice regarding truth-telling in the East and the West, specifically in Japan, the UK, and the USA. I also investigate contemporary practice regarding truth-telling in these countries. Many differences are observed among the three countries in terms of societal, cultural, and religious traditions. These disparities affect how the truth is told during the interaction between physician and patient in a medical context, within which medical ethics is embedded.

My particular focus is on the medical context of Japan, where various factors – including social conventions and cultural traditions – have influenced what patients at the end of life are told about their disease. Being a chaplain, I met many cancer patients in the process of dying who were struggling with how to understand what their physician had told them regarding the truth of their disease. Thus, I feel there is a need for the quality of interaction between them to be improved. Therefore, the thesis sets out to investigate contemporary practice in relation to the quality of physician-patient interaction in end of life care and in relation to the truth-telling practices of physicians in order to identify the barriers to effective communication and truth-telling and then to point to concrete strategies that can be employed to overcome these barriers.

Why should the truth about illness be mutually shared between the patient and the physician? Why is truth-telling vital to patients at the end of life? Because medical information is the basis of what the patient’s next action would be. This is particularly true of the patient who wants to make



his/her own decision based on what the physician has communicated about diagnosis, treatment, and prognosis. This is the core of patient-centered medical care. Since the latter half of the 20<sup>th</sup> century when the latest medical machines could be employed to prolong the patient's life, patients and their families have begun to think deeply about the relationship between (1) the truth of the patient's disease and (2) the patient's decisions / autonomy to be actualized. Thus, telling the truth has turned out to be the pivotal issue among (1) how the patient lives during his/her remaining time at the end of life; (2) how to apply alternatives for dying well; and (3) how the individual patient's voice is heard and actualized.

### **Structure of the thesis**

Now, I will briefly introduce the five chapters of this thesis. The first four chapters investigate the history of truth-telling and the practice of truth-telling in the UK, the USA, and Japan. The fifth chapter uses the evidence found in the first four chapters to summarise the factors that prevent effective communication about truth-telling at the end of life in the USA, the UK, and Japan, and to discuss ways to improve the quality and content of such interactions between medical personnel and patients.

Chapter One is entitled "Truth-telling in Medical Practice and its Research in the West". It begins with the history of medical ethics in the West, i.e., the Hippocratic Oath and the Bible. Then, the history of the understanding of truth-telling which emerges in medical practice is outlined using a literature review of available sources in English. Here we find that Dr. Cabot is the first to distinguish between truth-telling as it relates to diagnosis, treatment, and prognosis of disease. In terms of research studies into the practice of truth-telling in the medical setting, we find that most of the studies are conducted in relation to truth-telling to cancer patients. The first chapter surveys the history of truth-telling in medical practice from the turn of the twentieth-century to the 1970s. During this time period, there is evidence in the literature of a shift in attitude and practice away from medical paternalism and toward patient-centered medical practice. This is another strand in the history of the institutionalisation of truth-telling in medicine which is explored in the first chapter. One sees the emergence of the human rights movement which helped replace medical paternalism with patient-centered care. This presupposes the disclosure of full information to patients who are expected to have a say in their treatment programmes rather than passively accept the judgments of their physicians.

Chapter Two is entitled "Tracing the growing emphasis on truth-telling and patient-centered medical care in the West". This chapter continues the historical survey and literature review of truth-telling in medicine in the context of end of life care, taking account of research studies from

1980 to the present day. The chapter opens with an examination of the history of the hospice movement and palliative medicine, which contributed greatly to improved patient care at the end of life. This chapter includes surveys revealing patient experiences of and patient wishes towards truth-telling in medicine, and considers attitudes towards advanced directives (living wills). It also surveys the literature concerning admission of medical error, non-disclosure of information, withholding truth from patients, and physician deception.

Chapter Three, which is entitled “Japanese Tradition and its Impact on current medical practice in Japan”, turns to consider the societal and cultural context of Japan, and its strong influence on the nature of the country’s medical practice. The first part of Chapter Three offers an account of Japan’s traditional values. Japan has different cultural characteristics, norms, and expectations to those of the West. These features of Japanese society are explored, including its hierarchical structure, the Japanese household and family system, care of the elderly, and conventional gender roles. The nature of Japanese language and communication is outlined, as is the Japanese difficulty with imported abstract concepts. The second part of the chapter considers the characteristics of Japanese medical practice and bioethics, past and present. These include the Japanese approach to patient autonomy, the persistence of medical paternalism, end of life care, attitudes to death and dying, palliative medicine, and the hospice movement in Japan. The Japan Society for Dying with Dignity is introduced in the final part of this chapter, to show how patient wishes are being expressed in the contemporary Japanese context.

Chapter Four is entitled “Research into truth-telling and treatment practices in end of life care in Japan”. It examines research studies and national surveys of attitudes towards truth-telling and end of life care in Japan, and the practices and procedures of medical decision-making at the end of life – especially concerning the withholding and withdrawal of life sustaining treatment. I examine qualitative research as well as quantitative research into these practices, as published in major journals and books both in Japanese and in English. The chapter begins with Japanese Government research on the preferences of Japanese people on various aspects of end of life medical care. This is followed by analysis of research into how medical practices of truth-telling on diagnosis, treatment, and prognosis of disease have been executed in Japan, especially in relation to cancer. It examines the influence of the Japanese family on truth-telling practices in the medical setting, by way of the famous case of Dr. Yamazaki’s patient as an illustration. The second part of Chapter Four examines instances of good practice regarding truth-telling in medical settings in Japan. The third section examines the practice of withholding and withdrawing life sustaining treatment in Japan. In the fourth section, some of the notorious law suits concerning medical malpractice, where physicians acted without patient consent or information disclosure, are

discussed. In the final sections, the Japanese guidelines on the treatment of patients at the end of life are reported, examples of good practice with regard to truth-telling in Japan are highlighted, and the important function of nursing staff in being available to patients for their unasked and unanswered questions, are described.

Chapter Five is entitled “Developing trust and critical & creative contemplation (“CCC”) for truth-telling medical practice”. It aims to promote best practice in relation to patient-centered care at the end of life by identifying ways to improve communication in the medical setting, and therefore increase the likelihood of a full and frank discussion between the relevant personnel (physician, patient, family of the patient) concerning the diagnosis, treatment, and prognosis of the patient’s illness. The first part of Chapter Five identifies the blockages to effective communication in medical settings. The second part discusses ways to overcome these blockages. In particular, it examines ways to foster trust in the service of truth-telling in the physician-patient relationship. The third part proposes a reflective praxis I have named critical and creative contemplation (“CCC”) to develop insight and interaction between the providers and recipients of care. I believe – by promoting a better quality of interaction and engagement – that truth-telling will be fostered as to help patients empowered on making decisions about their treatment, care, and final days on this earth. Having outlined what CCC involves, I then show how this method could work in practice in relation to: (i) the patient at end of life; (ii) the family of the patient; (iii) the physician or medical team; and (iv) the chaplain. This is followed by a discussion of how CCC might relate to medical practice in Japan. The chapter closes with some reflections on how CCC can help prepare the patient for death.

### **Research materials and research strategy**

The research for this thesis was conducted in the form of a literature review, to provide a comprehensive survey of the relevant published and online materials, including research studies, surveys, newspaper articles, and social media. In terms of major sources for the research of the USA, the UK, and Japan, I used electronic databases, i.e., Medline, CINAHL, and PsycINFO, and major books about truth-telling with the following key words: compassion, egalitarian, God in the Bible, Hippocratic Oath, empathy, sympathy, telling truth of diagnosis, treatment, and prognosis to patient at the end of life and terminal patient, quality of daily life at the end of life, dignity of patient at the end of life, patient autonomy, paternalism, pain and suffering of patient at the end of life, palliative care, hospice, medical ethics at the end of life, philosophical, psychological, socio-cultural, and religious or theological meaning of death and dying, medical aspect of dying and death, euthanasia, trust of physician-patient relationship, telling a lie, physician’s education on communication, the history of medical practice, and physician-patient relationship at the end of

life. I tracked down studies from before the 1950s in the West based on the books and journals of the 19<sup>th</sup> and early part of the 20<sup>th</sup> centuries.

For Japanese-language data, I used Japanese blogs for the latest medical, legal, and societal problems of patients at the end of life: “Tengoku eno Visa” (“Visa to Heaven”) by Dr. Kotori, an internal physician, “Motoken Blog” by a former prosecutor who is currently a lawyer, “Songenshi Kyokai Blog” of “the Japan Society for Dying with Dignity”, and many other blogs in which patients, physicians, lawyers, and ordinary Japanese people participate. I examined how “anrakushi” (“euthanasia”), “songenshi” (“dying with dignity”), and any other related problems are reported in Japanese newspapers. Regarding Japanese books, I have included: Dr. Yamazaki’s best seller, *Byoin de Shinuto iukoto. (Meaning to die in Hospital: For patients, nurses, doctors and all other people)*, which looks at how terminal patients were treated when hospitalised; *Takasebune (The Takase Boat)* by Mori Ogai, physician and writer in the Meiji Era, which is a Japanese story intertwined with history and which is the best known novel for the interpretation of euthanasia from the perspectives of ordinary Japanese people; and major books in Japanese. These include titles only available in Japan regarding the history of Japan, the history of Japanese medical practice, psychology in the West and Japanese way of thinking, philosophy in the West and Japanese philosophy and/or tradition, ethics and medical ethics in the West and Japanese ethics and medical ethics, communication in the West and Japanese communication, language in English and in Japanese, socio-cultural-religious facets of human beings including patients at the end of life in the UK, the USA, and Japan, and any other related problems. The articles in Japanese that I have studied in detail include those from academic journals on terminal patients and patients at the end of life with any other related problems, i.e., “Nippon Ronen Igakkai Zasshi”, together with other major Japanese medical journals. The “Nihon Ishikai” (“Japan Medical Association”) driven article in 2004, “Ishi no Shokugyo Rinri Shishin” (“Guideline of Ethics to Physicians”), *Nihon Ishikai Zasshi*. 131(7): 1 – 46, is the most important document on the ethical responsibility of the Japanese medical doctor. Japanese monthly magazines, i.e., Chuo Koron’s January 2008 article on Healthcare, and Bungeishunju’s October 2007 and August 2008 articles on hospital corruption in Japan, are read as references.

### **The limitations of the present study**

There are limitations to this thesis. I intentionally limited my focus on truth-telling as a medical concept and its practice in relation to the patient at the end of life – with all its psycho-socio-cultural-religious facets – to the UK, the USA, and Japan respectively. Thus, approaches to truth-

telling used in the medical contexts of other countries are absent from this thesis. In reality, however, many of the issues discussed herein apply in other medical and cultural contexts.

The reasons for concentrating only on the above three countries are three fold: (1) regarding time and space of interaction with patient, his/her family, and interdisciplinary team of physician, nurse, social worker, psychologist, chaplain, and any other support staff in the UK, the USA, and Japan, I considered my direct experiences with them as the basis of the present work, (2) in terms of language applied for interaction, I only used English and Japanese to communicate with the patient, his/her family, and the interdisciplinary team of physician, nurse, social worker, psychologist, chaplain, and any other support staff in these three countries, and (3) concerning how to understand psycho-socio-cultural-religious facets of patients, I exposed myself to the Western culture in the UK and the USA as the reference to Japanese culture, while studying the following fields: philosophy, ethics, history, theology, medicine, psychology, communication, English and Japanese languages, and any other related subjects geared towards comprehending truth-telling as a medical concept and its practice, especially in relation to the patient and physician relationship.

## **Chapter One**

### **Truth-telling in Medical Practice and its Research in the West**

#### **Abstract to Chapter One**

The first chapter of this thesis begins with stating the historical importance of the Hippocratic Oath and the Bible in shaping the approach to medicine of Western physicians. It then turns to a consideration of the history of understanding the physician-patient relationship, rooted in the duty of nonmaleficence, to show how physician's attitudes to truth-telling emerged and developed from the sixteenth century to the twentieth century. These historical backgrounds within the West's medicine have worked as the prelude to shaping West's contemporary emphasis on patient-centered medical practice and the transparency of truth-telling driven interaction between physician and patient.

This chapter of the thesis is to illustrate truth-telling driven concept and its practice in medical settings in the West, with particular focus on the UK and USA. In terms of analysing ramifications of truth-telling, Richard Cabot M.D. is the pioneer who first declared in 1903 the importance of truth-telling in its three-fold aspects: in relation to diagnosis, treatment, and prognosis. Since Cabot's time, there have ensued many discussions on what Dr. Cabot proposed to his fellow medical doctors about whether and how to communicate the truth to patients.

The chapter then comprises a historical survey of hospital-based research into truth-telling mostly about cancer from the 1920s to the 1970s. It examines research into the truth-telling practices of physicians, and research on patient's attitudes towards truth-telling. This research reveals the growing interest in truth-telling within the doctor-patient relationship as the twentieth-century progresses.

The final section of this chapter connects the continuing importance of implementing truth-telling in medical settings together with the world-wide promotion of human dignity and the West's recognition of personal autonomy as the fundamental values of humane society. These values go hand in hand with the human rights, civil rights, and consumer rights movements that take place in the second half of the twentieth-century.

#### **1. The influence of the Hippocratic Oath and the Bible on medical practice in the West**

In the West, the way in which truth-telling has been understood and practiced in the medical setting cannot be comprehended without knowledge of the enormous influence of the Hippocratic Oath and the Bible. The Hippocratic Oath can be summarised in the famous principle to all physicians: "Do not harm patients". The Bible urges every one of us to ponder the meaning of

*agape*, unconditional love, and act it out through “love of neighbour” with any other human being in his/her own daily life. That is to say, the Western concept of medicine and its practice have developed in tandem with the history of medical ethics in the West.

Throughout the history of medical ethics, the Hippocratic Oath has been the benchmark or standard for physicians in the West. The Hippocratic Oath requires physicians to act for and in the best interests of their patients, i.e., not to do harm and to relieve their patients of pain, while preserving confidentiality. On nonmaleficence and beneficence Tom Beauchamp and James Childress state:

The Hippocratic oath clearly expresses an obligation of nonmaleficence and an obligation of beneficence: “I will use treatment to help the sick according to my ability and judgment, but I will never use it to injure or wrong them” (Beauchamp, T. and Childress, J. 2009: 149).

This context-free text of the Hippocratic Oath is to be used for any context-driven medical practice. Thus, context-driven “practical ethics” for medical practice rather than just context-free “medical ethics” should be sought and ascertained for the purpose of saving the life of the patient through the timely and constructive interaction between the patient and the physician. With regard to telling the truth, the Hippocratic Oath does not state that physicians should not tell a lie to their patients. In terms of the patient-physician relationship, trust is the essential factor for physicians to cultivate with their patients. Thus, misleading without lying about their patients’ illnesses is not recommended in order for physicians to genuinely help their patients. However, in real medical settings, there are many cases where the truth has been partially told to patients, out of consideration for the patient’s specific context. Thus, it is necessary to ponder the grey area between telling the truth and telling a lie, together with the consideration of the patient’s sensitive feelings and vulnerability in relation to their terminal disease and/or to the end of life.

In the history of Western medicine, the Bible is the other essential source which has led conscientious physicians in the West to ponder what medical practice ought to be in terms of the relationship between physician and patient, while helping relieve the patient from disease. The Bible has been the eternal and timeless best seller which gives us all insights into how to deal with both the good and bad sides of human nature and the psychology of human beings, regardless of where they are. The fundamental messages of the Bible that should be acted out by Christians include: to appreciate God who is ubiquitous, to serve their neighbours, and to love their neighbours. The Christian church in the West has functioned as the societal infrastructure, shaping values and practices aiming to bring about “common good” for everyone, i.e., the history of hospitals cannot be explained without Christians helping one another with *agape*.

In the Bible, among countless essential teaching materials, the most crucial statements in terms of truth-telling include: (1) “God created man in his own image” (Genesis 1:27) in order to establish the basis of a human being’s worthiness from God’s viewpoint, (2) “Hope deferred makes the heart sick” (Proverbs 13:12) which emphasises hope as an important ingredient of human well-being, and (3) “Truth makes man free” (John 8:32) which says that truth should be sought out by human beings throughout their entire lives. The parables of the Bible, through the interaction between Christ and human beings, can wisely illustrate: (1) that to which each one of us should pay attention in our own daily life, (2) how we should interact with one another, and (3) why we should treat other individuals as equal, while showing respect at the same time. I believe that the Bible is full of merits concerning real encounters with strangers. Thus, truth-telling needs to learn from the merits of the Bible to genuinely act out humane relationships between physician and patient. Thus, I believe that the Hippocratic Oath and the Christian tradition both pave the way for the importance placed on physicians telling the truth to their patients.

## **2. Historical approaches to patient care and truth-telling in medical practice in the West**

In terms of medical education, it was in 1518 when the College of Physicians of London was established. Medical doctors in England, however, were competing with each other by claiming that their treatments were preferred to those of other doctors. Under such circumstances, how best to treat the patient became the key issue.

The actual treatment used became an ethical issue. Both the Christian and the Hippocratic doctor agreed that the patient should not be harmed, the disagreement, however, lay in what was good for the patient, and what constituted harm. This was expressed through a mixture of technical medical language and ethical values, the boundaries between the two being, because of the nature of the disagreements, imprecise (Wear, A. 1993: 119).

What interests me in this statement is that both the Christian and the Hippocratic doctors agree not to harm the patient, but disagree on how to benefit the patient. In many respects, this dilemma remains up until the present day.

In the late 16<sup>th</sup> and early 17<sup>th</sup> centuries, plague was the problem in the Netherlands and in England. Thus, physicians in these countries were struggling with whether or not to disclose the plague to the patient as the truth of diagnosis.

Might the physician be morally entitled to keep the truth from those of his patients who had caught the plague when the outbreak of the disease had yet to become common knowledge, if he perceived it to be in the interest of the Commonwealth? Or might he withhold his suspicions about an oncoming epidemic from the general public for the sake of peace and stability? (Grell, O. 1993: 134 – 135).



Here the motivation for withholding information was not to protect the wellbeing of the patient per se, but to strategically safeguard against any social panic.

In England, Thomas Gisborne (1758 – 1846), a graduate of St. John's College at Cambridge, wrote on moral theology and moral philosophy. Gisborne advocated the importance of telling even a little truth to patients. His book, *An Enquiry into the Duties of Men*, first published in 1794, discusses the duties of the physician with regard to truth-telling.

The physician is invariably bound never to represent the uncertainty or danger as less than he actually believes it to be; and whenever he conveys, directly or indirectly, to the patient or to his family, any impression to that effect, though he may be misled by mistaken tenderness, he is guilty of positive falsehood. He is at liberty to say little; but let that little be true (*An Enquiry into the Duties of Men* vol. ii, 160 – 161; cited in Porter, R. 1993: 261).

As the physician who studied theology and drafted the first modern code of medical ethics, the Englishman Thomas Percival (1740 – 1804) influenced the Medical Associations' Codes of Ethics in both the UK and the USA. One of Thomas Percival's principles of medical ethics states that "a physician should be the minister of hope and comfort to the sick" (Leake, C. 1975: 186). I will argue that this duty still applies today, and that truth-telling and the establishment of trust between medical doctor and patient are integral parts of that duty.

William Osler M.D. was a Fellow of the Royal Society, a Fellow of the Royal College of Physicians, London, Professor of Medicine at Johns Hopkins University, and Physician-in-chief at Johns Hopkins Hospital, Baltimore, USA. In the 3<sup>rd</sup> edition of Dr. Osler's textbook in 1899, familiar medical terminology from today's clinical practice, i.e. palliative medicine, quality of life, sedation, and patient-centered medical practice, was non-existent. The focus was on diagnosis, symptomatology, and treatment (Osler, W. 1899: preface). The emphasis, in other words, was not patient-based, but doctor-based. The patient is practically invisible. This example illustrates the shift in emphasis throughout the centuries of medical practice in the West whereby physicians progressed from concentrating purely on disease to concentrating on each patient as an individual.

Dr. R. Cabot wrote the following candid comment on the relationship between the Hippocratic Oath and contemporary physicians whilst working at the Massachusetts General Hospital in Boston, Massachusetts, USA in the early part of the 20<sup>th</sup> century.

The Hippocratic oath dates from the time of the founder of medicine four hundred years before Christ. It is a curious mixture of sound sense, valid for all time, and

of pledges which have no application to modern medicine. In it the doctor promises that he will not operate on anyone for stone in the bladder but “will give way to those who work at this practice” --- a form of trade unionism not popular among physicians today (Cabot, R. 1926: 35 - 36).

Regarding the statement above, Dr. Cabot had a very clear insight into the following two points: (1) the gap between the time when the Hippocratic Oath was made and its application to modern medicine and (2) the nature of physicians to stubbornly resist the formation of a trade union in the early 20<sup>th</sup> century. At this point, let me explain more about Dr. R. Cabot, as the physician who proposed three kinds of truth-telling to patients.

### **Richard Cabot M.D.**

Concerning the history of truth-telling to the patient, in the early part of the 20<sup>th</sup> century, Dr. R. Cabot was the medical pioneer who advocated the importance of truth-telling of diagnosis, treatment, and prognosis. Since then, arguments for and against truth-telling have been conducted up until the present day. Rather than simply advocating that physicians tell the truth in all circumstances, there is the question of the appropriateness of truth-telling to all patients in every situation. Since the basis of medical practice is not to harm patients, one must ask: “What does it mean exactly to harm the patient in the real clinical context?” “Who is responsible for deciding what causes or constitutes harm?” and “Would truth-telling in this specific context cause harm?” In reality, the patient’s autonomy is at odds with the physician’s discretion, due to tangible and intangible problems brought about by truth-telling. Now, in order to listen to what he advocates, I will begin to talk about Dr. Cabot at Cambridge, the historical city in the state of Massachusetts in the USA.

Dr. Richard Cabot of Harvard Medical School was the first to address truth-telling and its repertoires in the context of his candid confessions backed up by his own clinical practice. It was in 1903 when Dr. Cabot proposed the three classifications of telling the truth to patients.

I propose ... to examine the matter more in detail, considering: (1) truth in diagnosis; (2) truth in prognosis; (3) truth in treatment ... By telling the truth I mean doing one’s best to convey to another person the impression that one has about the matter in hand. One may do one’s best and yet fail, but that is not lying (Cabot, R. 1903: 345).

Dr. Cabot also admitted that, in exceptional circumstances, the truth could be withheld from patients, or even a lie may be told. The following is his explanation about when a lie might be allowed.

Very few Americans like to lie. They would rather tell the truth if they could, but there are cases in which the voice of duty itself seems to tell us that we must lie. To prevent the breaking up of a family, to save a life, are we not to lie? (Cabot, R. 1903: 346).

In Dr. Cabot's terms, the truth is the physician's actual impression of the patient's disease based on the physician's own judgement, as he states:

So in medicine, if a patient asks me a straight question I believe it works best to give him a straight answer, not a rough answer, but yet not a lie or a prevarication. I do not believe it pays to give an answer that would justify a patient in saying (in case he happened to find out the truth): --- "that doctor tried to trick me." I have heard a patient say that, apropos of a lie told by one of the most high-minded and honorable physicians I know, and I do not believe it advisable for any of us to expose ourselves to the chance of rousing that sort of indignation in a patient ... But a straight answer does not mean for me what is often called the "blunt truth," the "naked truth," the dry cold facts. The truth that I mean is a true *impression*, a fully drawn and properly shaded account such as is, as I well know, very difficult to give (Cabot, R. 1903: 347).

Here, I believe Dr. Cabot demands that physicians ponder the mechanics of telling the truth in interactions with patients.

Cabot's research into truth-telling led him to conclude that, however difficult, honesty was always the best policy.

I will sum up the results of my experiments with truth and falsehood, by saying that I have not yet found any case in which a lie does not do more harm than good, and by expressing my belief that if anyone will carefully repeat the experiments he will reach similar results. The technic of truth telling is sometimes difficult, perhaps more difficult than the technic of lying, but its results make it worth acquiring (Cabot, R. 1903: 349).

Half a century later, the Dean of Harvard Divinity School, W. Sperry, mentioned what Cabot's truth-telling looks like:

There is no single categorical answer to the question, "Shall the patient be told the truth?" Dr. Richard Cabot was, as most of us remember, the dauntless soldier of utter sincerity. He was probably more nearly right than wrong, but he seemed at times to overstate his case. Here is an area where the paths of the doctor and the minister cross, though they may not always catch sight of each other in passing (Sperry, W. 1951: 110).

Dr. Cabot confessed the great merit of frankness by citing the part of the address to medical students given by Sir Frederick Treves (1853 – 1923), the London surgeon known for having rescued Joseph Merrick, the “Elephant Man”. Treves told the students that:

a certain profession of dogmatism is essential in the treatment of the sick. The sick man will allow of no hesitancy in the recognition of disease. He blindly demands that the appearance of knowledge shall be absolute, however shadowy and unsubstantial may be the basis of it (see Cabot, R. 1903: 345).

This quotation from Dr. Cabot illustrates patients’ earnest desire for their disease to be diagnosed. However, it also speaks of a certain paternalistic tendency of physicians in their dealing with patients, and a desire to maintain their authority even when certitude is missing.

Cabot and Dicks helpfully outline some of the virtues of a good physician when communicating with patients. Listening is the key to understanding well what the patient says.

We listen with our limitations and our biases, as well as with our good sense, and to this extent our listening is as much as a failure as if our hearing were impaired. Then, we are bored, unsympathetic, discouraging, or off the point in our replies (Cabot, R. and Dicks, R. 1936: 192).

The help that a doctor can give a patient to think and talk does benefit both the doctor and the patient. For example, when the patient has the opportunity to voice his/her own concerns, the doctor can directly hear the patient’s further problems.

Directed listening [to lead the patient to think and talk about a definite subject] may be used to get information when we suspect that the patient has something on his mind which is causing him concern. Or we may use it to get a patient to express an opinion which will turn his mind into a desired channel of thought (Cabot, R. and Dicks, R. 1936: 199).

## **W. Alvarez M.D.**

Half a century later, Dr. Alvarez, emeritus consultant in internal medicine and emeritus professor of medicine at the University of Minnesota, Mayo Foundation, with forty five years of medical experience, recommended the practice of truth-telling in the medical context. Regarding telling the diagnosis to the patient, he advised “withholding the diagnosis until the reports of tests are all in ... A physician should never give even an intimation of his opinion until the results of all the tests are in” (Alvarez, W. 1951: 531). Physicians should never disturb the patient by speculating on the diagnosis: “Thinking aloud before a patient as we make the differential diagnosis and telling of all the awful diseases he or she could have is a pernicious habit. It is terribly hard on the nerves of the victim” (Alvarez, W. 1951: 146). Furthermore:

the physician need not always give a definite diagnosis of organic disease ... In many cases no definite diagnosis can logically be made, and certainly not at the first interview ... Sometimes all I can say is, 'Take a rest, and make sure that the distress is not due to the eating of some food, and if you are not soon on the road to recovery let me see you again' (Alvarez, W. 1951: 508).

Alvarez emphasises the importance of knowing and understanding patients before offering diagnoses. The role of the physician is not to tell all the truth from the physician's perspective, but to tell the truth in a way that takes into account the patient's capacity to absorb it. Thus, telling the truth could be mitigated depending on the capacity of the patient once that is perceived by the physician. Not telling all the truth would be justified if the physician has determined the extent of understanding the patient might have in the specific context. The physician may need to invest time to help the patient fully understand the details of the disease. The same applies when explaining treatments to patients: "If a physician would only take time to explain to his patient what needs to be done, or what was done, or why it was done, and what it showed, things would go much more smoothly" (Alvarez, W. 1951: 509). Concerning prognosis, Alvarez recommends letting patients know that it is not an exact science: "we [physicians] should cheer many patients by telling them of the many cases we know of in which a bad prognosis turned out to have been all wrong" (Alvarez, W. 1951: 146).

Alvarez rejects telling a lie to the patient.

One of the most difficult problems facing the physician is how far he can safely go in the way of discussing the patient's illness with him. Usually the family asks that the physician deny that there is anything to worry about, and ordinarily he complies, if only because at college he was trained to follow this course. I think, however, that most such medical lying is wrong, usually futile, and even harmful (Alvarez, W. 1952: 86).

In summary, the essences of a good physician are to guard his own tongue (Alvarez, W. 1951: 145) and to give hope to the patient enough to create his or her future plans (Alvarez, W. 1951: 580). The following is Alvarez's suggestion to the family of a patient with an incurable illness:

Usually some little hope can be given. The diagnosis could be wrong, or radiation or some drug may help, or a new and effectual drug may come in time ... After talking with the patient it often helps to talk to the family. I often say to an old couple, "You two have gone through forty years of travail, sorrow, and joy, hand in hand, sharing everything; now when one of you has to go down through the valley of the shadow, why shouldn't you go through that also, hand in hand? Why should you be lying to each other, and making believe you do not know what the loved one has? That can give rise only to loneliness" (Alvarez, W. 1951: 581).

Thus, hope can be used to justify the reasons for both telling the truth and not telling the truth to the patient from the viewpoint of any other persons related to the patient. That is why telling the truth is such a difficult business with which to deal for any individual persons concerned with patients. These matters will be discussed in future chapters.

### **Other physicians' policies: Truth withheld or told depending on the patient**

What follows are major tendencies among American physicians on withholding truth from patients or considering what and how to tell the truth to each patient.

#### **M. Seelig M.D.**

Dr. M. Seelig, who was the Director of Pathology of The Barnard Free Skin and Cancer Hospital, delivered a paper to The Barnard Free Skin and Cancer Hospital Conference on December 7 in 1942, stating that:

I have yet never told a patient that his disease was cancer, except in those very few instances in which it was necessary to do so for special personal reasons or in order to shock him into a cooperative state of mind (Seelig, M. 1943: 33).

#### **William Henry Welch M.D.**

Dr. William Henry Welch was chair at Johns Hopkins and one of the Welch physicians of Norfolk in Litchfield County, Connecticut. He contributed to bacteriology and discovered a bacillus which was named "Welch bacillus". Welch was "a man of study and of uncomfortable truth-telling, and the spokesman for change and innovation. Compassion, generosity, and kindness he shared with them [the Welch physicians]" (Fleming, D. 1954: 3). Welch died of cancer at the age of 84 on April 30 in 1934, after being hospitalised in the Johns Hopkins Hospital in February in 1933. Perhaps he knew his condition was terminal, since Welch, we are told, when hospitalised as a dying patient.

remained uncomplaining and alert and kept his doctors enthralled with recollections of the past. He never asked any questions about his condition and made no gestures toward religion. Biologists, he said, were more skeptical than physicists, and few biologists had any conception of life after death (Fleming, D. 1954: 202).

This case raises the question of the wishes of patients regarding whether they want to know about their medical condition. As B. Sachs states, "the doctor should know; the patient need not know" (Sachs, B. 1942: 324).

### **Charles Lund M.D.**

According to Dr. Charles Lund of Boston, writing in the mid-twentieth century, telling the truth is unfeasible:

Since telling the truth is impossible, there can be no sharp distinction between what is true and what is false. But surely that does not relieve the physician of his moral responsibility. On the contrary the difficulties that arise from the immense complexity of the phenomena do not diminish, but rather increase, the moral responsibility of the physician ... Far older than the precept, 'the truth, the whole truth, and nothing but the truth,' is another that originates within our profession, that has always been the guide of the best physicians, and, if I may venture a prophecy, will always remain so: So far as possible, 'Do no harm.' You can do harm by the process that is quaintly called telling the truth. You can do harm by lying. In your relations with your patients you will inevitably do much harm, and this will be by no means confined to your strictly medical blunders. It will also arise from what you say and what you fail to say. But try to do as little harm as possible, not only in treatment with drugs, or with the knife, but also in treatment with words, with the expression of your sentiments and emotions (Lund, C. 1946: 956).

The above statement raises many core questions about telling the truth to patients, together with how to deal with the principle of nonmaleficence and how to define the truth in the individual patient's context. The physician's utterance, body language, and any preconceived ideas towards a patient can be communicated and/or interpreted by the patient. Thus, what the physician should do, before interaction with any patient, is to thoroughly consider the psychology and background of the individual patient.

Between the two contrasting camps of physicians: (1) telling the truth to patients (Cabot and Alvarez) and (2) withholding the truth (Seelig, Welch, and Lund), there stands the position of L. Henderson and B. Meyer as the main physicians advocating that the feelings, emotions, and/or needs of the individual patient are to be considered in every interaction with a patient and in whatever is told to the patient.

### **L. Henderson M.D.**

The following are the core points in Dr. Henderson's address delivered at the Harvard Medical School on December 20, 1934 and at a Medical Staff Meeting of Massachusetts General Hospital on January 21, 1935 in which he recommended that his fellow physicians stick to the feelings and emotions of the patient during interactions. He coined the expression "a social system" to describe the patient-physician relationship.

A physician and a patient make up a social system. And that is my first point. In any social system the sentiments and the interactions of the sentiments are likely to be

the most important phenomena. And that is my second point ... The physician should see to it that the patient's sentiments do not act upon his sentiments and, above all, do not thereby modify his behavior, and he should endeavor to act upon the patient's sentiments according to a well-considered plan. And that is my third point (Henderson, L. 1935: 819 – 823).

## **B. Meyer M.D.**

Dr. B. Meyer also claims the complexity of the individual patient's mental condition can be used to pinpoint what would be relevant regarding whether and how to communicate with the patients about their disease.

Indeed, the problem must be answered in terms of the individual need of the patient, and if the surgeon himself is unable to make an appropriate decision, it may become the role of the psychiatrist to determine who should tell what truth to which patient (Meyer, B. 1958: 209).

In the similar milieu of mental conditions which are expected to further deteriorate in serious stages of mental disease, with questions: (a) what kind of truth should be told to, and (b) what sort of words should be used for the specific individual patient, Dr. Rothman's comment on where the insane were treated in the USA in the 19<sup>th</sup> and 20<sup>th</sup> centuries would be helpful. This is largely because the history of the relationship between asylums and hospitals can illustrate that the asylum of the nineteenth century became the hospital of the twentieth century. For example, the asylums of the past changed and became treatment hospitals as the model of a treatment hospital was being tested (Rothman, D. 1980: 335).

In the West, up until the 1970s, the medical practice of truth-telling was mainly focused on telling the diagnosis, followed by the method of treatment; the prognosis was rarely told. It is my opinion that telling the truth of diagnosis, treatment, and prognosis should be executed to genuinely help the patient make his/her own best possible decision, thereby patient autonomy will be fully accomplished in his/her respective medical context.

Truth-telling is very difficult for physician when treating terminal patients and/or patients at the end of life because the patient tends to interpret the diagnosis of cancer as a death sentence. Thus, whether or not to tell the truth of diagnosis and/or prognosis to a patient would be extremely problematic at any given time, as H. Solomon points out "the question of what to tell a patient in the tentative or certain diagnosis of cancer has bothered physicians for generations" (Solomon, H. 1947: 803).



As the executive officer of the Mississippi State Board of Health, USA, Dr. F. Underwood was involved in educating people through “the campaign for cancer control” in 1949. Cancer, he explained, is “an intensely personal disease”, but a cancer diagnosis need not be a death sentence, because “Today there is good news about cancer, in that newer, bolder techniques in surgery have made operations safer, the percentage of cures higher and the chances of complete recovery much greater when early diagnosis and adequate treatment is secured” (Underwood, F. 1949: 280). In terms of cancer as an individual business, L. Piatt poses the sensitive question of whether and when to disclose a cancer diagnosis to a patient, as stated below.

What shall the cancer patient be told? There is no general answer to this question. Each case is an individual one and what is to be told the patient depends on the personal temperament of the individual. If the cancer has been recognized early and there is a good probability of a cure, the patient may be told, so that after-care and repeated examinations may not be neglected. Prophecy in malignancy as to life expectancy is notoriously difficult. If, on the other hand, the cancer has progressed to the stage of incurability or hopelessness, then it would seem that it would not be best to tell the patient all the facts unless circumstances warrant otherwise. The necessity of arranging one’s financial matters might indicate telling the patient the true conditions (Piatt, L. 1946: 372).

Therefore, what to tell patients is also subjective, depending on the temperament and needs of each unique patient. Truth-telling was crystallised on cancer-based discussion around the cancer patient’s diagnosis and treatment at the end of life, particularly as shown by the example below.

Truth-telling triggers the patient to change his/her life from one day to the next, as well as creating stress for the patient. Thus, the physician has to face the challenge of whether or not an extremely serious diagnosis should be directly delivered to a terminal patient. The following is a legal case from England and USA, initiated by the patient because of the inaccurate diagnosis given in the 1940s, summarised thus:

The Court of Appeal reversed on March 21 the decision of Mr. Justice Birkett which awarded £6300 damages against a surgeon for what was alleged to be a negligent diagnosis. The facts may be briefly recalled. Mr. Whiteford, an American engineer practising in England, complained that in 1942 he consulted a practitioner and a surgeon (Dr. S. R. Gleed and Mr. J. B. Hunter) and underwent operations on March 22 and April 5, and that he was informed that he had cancer and had only a short time to live. He said that, in view of that diagnosis, he wound up his practice and returned to America to die; in New York, however, he took fresh medical opinion and it was found that he was suffering not from cancer but from chronic cystitis and a considerable bladder diverticulum. The defendant surgeon denied liability. He admitted having diagnosed a cancerous growth in the bladder, but he pleaded that he did so after a careful manual and visual examination of the bladder and after taking all steps reasonable and practicable in the circumstances to check his diagnosis. The defendant practitioner (against whom the action for alleged negligence was dismissed by Mr. Justice Birkett) contended that he was acting

under the surgeon's instructions at the two operations. The law does not assume that medical practitioners guarantee accurate diagnosis (Medicine and the Law: Surgeon's Successful Appeal. 1949: 586).

Here, let me introduce the event that changed the history of medical practice in the West and which was courageously initiated by the American patient in the 1950s. I believe the history of truth-telling cannot be completed without telling the origin of how informed consent was created. Historically, the phrase, "informed consent", was used for the first time in the USA by Justice Bray on the 22<sup>nd</sup> of October, 1957 in the lawsuit of *Salgo v. Leland Stanford Jr. University Board of Trustees* (1957), when Justice Bray stated that "in discussing the element of risk a certain amount of discretion must be employed consistent with the full disclosure of facts necessary to an informed consent" (cited in Katz, J. 1984: 61). Accordingly, *Salgo* launched the new way of making the American medical community leave behind "its feudal practices" (Katz, J. 1984: 65). However, it took more than 20 years between the Bray ruling and informed consent being officially adopted in 1981 when the expression "informed consent" was used by the Current Opinions of the Judicial Council in the American Medical Association.

Thus, ideally all the facts of each patient should be considered, as stated below.

Good general diagnosticians are rare, not because most doctors lack medical knowledge, but because most are incapable of taking in all the possibly relevant facts --- emotional, historical, environmental as well as physical. They are searching for specific conditions instead of the truth about a man which may then suggest various conditions. It may be that computers will soon diagnose better than doctors. But the facts fed to the computers will still have to be the result of intimate, individual recognition of the patient (Berger, J. and Mohr, J. 1967: 68).

The above statement describes the challenges involved in correctly diagnosing a patient's disease. It also indicates that understanding all the facts about the patient is important in addition to taking the history of the patient's disease. In reality, however, few physicians can do everything that would ideally be expected.

### **3. A historical survey of hospital-based research into truth-telling concerning mainly cancer from the 1920s to the 1970s**

What follows is an investigation into the history of hospital-based research into physician-patient truth-telling about disease. Truth-telling about diagnosis, prognosis, and treatment arises as a medical concern and a research interest in the context of mainly cancer diagnoses. It is therefore cancer-based research where discussions of and research into truth-telling arises. In terms of what purpose is targeted for research on truth-telling between the beginning of the 20<sup>th</sup> century and the

1970s: firstly, there are studies on particular diseases, mainly cancer, which investigate characteristics of diseases and total numbers of patients with each disease; secondly, the attitudes of physicians towards telling the truth are investigated in different contexts; and thirdly, the responses of patients are described when the truth was told to them.

Let us begin chronologically with cancer research in the 1920s. Gastric ulcer and inoperable cancer were investigated by the Mayo Clinic, USA, in the 1920s. This study was conducted to match the name of the disease with the number of patients who had the disease. The 100 patients with gastric ulcers who were operated on at the Mayo Clinic in 1925, 1926, and 1927 were broken down into three classifications: those having the disease of “ulcer, vague, fair ulcer, and gallbladder disease combined” (23 patients); those with “ulcer, vague, and fair ulcer combined” (12 patients); and those with “less complicated illnesses” (65 patients). The 100 patients with inoperable cancer of the stomach explored at the Mayo Clinic in 1926 were classified as: those with the disease of “carcinoma, vague, and ulcer, obstruction combined” (15 patients); those with “carcinoma, vague, and ulcer, anemia combined” (12 patients); and those with “less complicated illnesses” (73 patients). Gastric ulcers which could be operated upon and inoperable cancer of the stomach were the two major illnesses, meaning that those suffering from them composed the first and second highest number of patients with cancer-related diseases (Alvarez, W., 1931: 79).

Regarding the treatment of gastric ulcers, gastro-enterologists at the time believed in the thesis that it was not a dangerous illness that needed to be treated medically. Thus, when they made the diagnosis of an ulcer, they considered ulcers as craters, whereas cancers were as tumors. (Here, let me put a note that the author, W. Alvarez, only used the American spelling of tumors in his original documents.) No relationship was created in their minds between a crater and cancer. It did not occur to them that a crater may be part of a cancer; they were not prepared for the idea and, as a result, when they received the roentgenologist’s report of “ulcer”, they unconsciously associated it with the adjective “benign” (Alvarez, W., 1931: 78).

I believe that the above research and reflection are important as products of the 1920s and the 1930s when the focus was only on understanding the diseases rather than on telling the patients about their illnesses.

In 1931, gastric cancer was studied in 41 physicians in the Mayo Clinic, USA. This study of physicians as patients was conducted on 41 physicians with cancer of the stomach in Rochester, Minnesota, USA, in 1931. What interested Dr. Alvarez was:

how physicians behave when they discover in themselves the first symptoms of the disease. I wondered if they would recognize the symptoms any earlier than they do when the disease occurs in their patients (Alvarez, W., 1931: 79).

Some of the physicians' own behaviours were really devastating. A physician whose mother died of cancer of the stomach made herself lose 40 pounds (18kgs) and tried not to obtain a diagnosis until one year later. A proctologist, as a patient, had indigestion for twenty-five years and later died. One physician was too busy to bother about his own health, so no treatment was provided for two years. Another physician eventually came to check on a condition which, for forty years, had caused him to suffer distress after meals for an hour; the condition was diagnosed as inoperable cancer.

Accordingly, 21 physician-patients had ulcer problems related to cancer, as Alvarez noted: "We have, then, the question of ulcer intruding itself into the diagnosis of cancer of the stomach in twenty-one of the forty-one cases" (Alvarez, W. 1931: 83). The following statement makes me feel scared and chilly, even though the comments of physicians in the 1930s are valuable in terms of their own candid reflections on whether or not the disease could have been diagnosed earlier.

The general practitioner or the physician in the small town is not the only one who needs to brush up on the diagnosis of cancer. Unfortunately, even those of us who work with every diagnostic facility at our command fail occasionally to recognize the early symptoms and signs of the disease. We do this because sometimes the trail is too faint to see, sometimes we are blinded by preconceived ideas about ulcer, and sometimes we are not sufficiently thoughtful or careful (Alvarez, W. 1931: 80).

Thus, we cannot rely on medical doctors who would not be able to recognise their own cancer at the onset stages, as well as their patients' initial conditions of cancer, i.e. a benign ulcer.

In 1947, the role of "history taking" in diagnosis was surveyed in Manchester, UK. How are diagnosis and "History-taking" connected? Based on his own long experience with many patients, i.e. 68 out of 100 patients helped on diagnosis in 1947, Dr. Platt, professor of Medicine at Manchester University, UK, suggested the importance of taking the history of the patient. He differentiated between good doctors and bad doctors with regard to two details: the time which they devoted to history-taking, along with their ability to interpret a history correctly, and their ability to formulate a plan of treatment (Platt, R. 1947: 305).

Dr. Platt explained that 68 out of 100 patients had no change in the diagnosis which had resulted from examination or investigation, meaning that the diagnosis reached after history-taking alone was unchanged, as shown in this example:

Diagnosis after history: bronchiectasis.

Examination: basal rales.

X ray (bronchogram): bronchiectasis.

Additionally, six patients were also revealed as having substantially correct diagnoses after their history-taking was executed. Thus, he advocated the importance of the time invested by medical doctors in taking the history of patients' diseases. I highly value history-taking as the first step towards sharing the same background information on the patient's disease between patient and physician, which might lead to a good human relationship.

### **Research into physician's attitudes and practices concerning truth-telling**

In 1953, a study of physicians was conducted in Philadelphia, USA, on how physicians' attitudes have changed towards telling the truth. Thirty-one percent of physicians told the diagnosis of cancer to their patients in Philadelphia in 1953. In this study of whether or not physicians communicated the telling of cancer diagnoses, questionnaires were mailed to 444 physicians. 82% of the answers from the 444 physicians were considered appropriate to be analysed.

In terms of telling cancer to patients, the physicians varied, i.e. only 3% (three percent) of them always told the patient the cancer diagnosis, whereas 28% of them usually informed their patients. Ninety-four percent (94%) of the dermatologists in this study tended to tell cancer, because no death was anticipated as a result of the cancer, no emotional reaction was expected, and skin cancer was considered relatively benign.

As it was often thought that cancer was a death sentence in the 1950s, USA, words like "tumor" were often preferred.

The physician should use such terms as "abnormal tissue growth" or "tumor" ... I feel strongly against letting the patient know he has cancer! To all people, intelligent or not, the word cancer means a death sentence (Fitts Jr., W. and Ravdin, I. 1953: 903).

However, two elements were beginning to cause mistrust: not telling cancer, and deception exercised by the physician, as stated below:

I always tell the patient he has cancer. In forty years I have had only two instances where the full truth was not well received. You can create distrust in the profession or bitter loss of faith in the family if deception is practiced by anyone (Fitts Jr., W. and Ravdin, I. 1953: 903).

Here, I can see trust vs. deception is closely connected with whether cancer is told. In turn, trust between physician and patient can only be created by sharing the truth, no matter how difficult it is to face that truth; this should be followed by the confirmation of the truth between them.

The patient needs a deep confidence in the physician ... Equally important that the physician have a deep respect of the patient ... The doctor-patient relationship

can be strengthened when there is mutual sharing and knowing together a painful truth. Otherwise, a painful barrier can be built up (Fitts Jr., W. and Ravdin, I. 1953: 903).

In the above statement, I wonder if trust and relationship could be used interchangeably. If so, I totally agree to the point that the relationship and trust between the patient and the physician are mutually strengthened by the process of exploring the shocking truth together. In terms of the relationship between cancer and suicide, three patients were reported to have committed suicide as a direct result of their cancer told.

However, since hope was expected by patients, physicians were seemingly struggling with a way of telling cancer to next of kin, if cancer could not be told to patients.

Most patients and almost all people who have discussed this problem with me have expressed a hope that they would be told the truth. Most families of patients, on the other hand, have actually asked that the patient not be told. In theory I believe that we should tell all patients except when there are definite reasons for not doing so. I think that those reasons need clarification. I do not know which patients I might make feel worse by telling, and therefore, I do not know with confidence which patients to tell (Fitts Jr., W. and Ravdin, I. 1953: 904).

I believe that telling the truth is beneficial for the patient. Later, I will explore the role of the family in the care and decision-making process.

In 1961, based on questionnaires and interviews with 219 physicians in Chicago, USA, Oken revealed that ninety percent (90%) of physicians preferred not to tell cancer to their patients.

For three-quarters of them, clinical experience was the major policy determinant, as the answers to the question, "How did you acquire your policy?" (Check every item which applies): "A. Taught you in Med. School"; "B. Taught you during Clinical Training?"; "C. Clinical experience"; "D. Non-professional experience with ill friends, family etc."; and "E. Other (specify)".

In the question, "If you were the patient, do you think you would want to be told?", "Yes" was the answer from the majority of the physicians.

The doctors wish to be told if he were the patient. As expected, those who tend to tell their patients wished to be told themselves, more often than those who do not tell. But the total number of those who said they wished to be told (73 of 122) is far greater than those who tend to tell their patients (Oken, D. 1961: 1125).

While "People continue to think of cancer as the killer" (Oken, D. 1961: 1126), physicians thought of fatal illness as a major defeat.

Practicing physicians are not the kind of persons who can sit quietly by while nature pursues its course. One of the hardest things for a fledgling medical student

to learn is watchful waiting. Few situations are as frustrating as sitting by impotently and “helplessly” in the face of illness. Fatal illness is felt as a major defeat (Oken, D. 1961: 1126).

Silence talks during the interaction between the patient and the physician.

With his own tendencies to deny what he must greatly fear, the patient may take his cue from the doctor’s silence as confirmation that the situation is hopeless and therefore better shunned. Tactful wishes to spare his distraught physician even may play a part (Oken, D. 1961: 1127).

Education for physicians was needed on how to face, manage, and deal with their own emotions, as stated, “Perhaps the doctor, more than the patient, should be a target for emotional re-education” (Oken, D. 1961: 1128). I believe this is an important point.

What was the true kindness to patients? To face the reality of the lack of understanding of cancer and to communicate with cancer patients would help physicians ponder “how to be *truly* kind to our patients” (Oken, D. 1961: 1128). I believe that Oken tried to let his fellow physicians think thoroughly how truth-telling should relate to the mission of physicians.

In 1977, a study of truth-telling was made in Rochester, New York, USA. According to the Journal of the American Medical Association, JAMA, in 1979, a study conducted in the year of 1977 showed that 98% of university-hospital medical staff (among 264 respondents) in Rochester, told patients about their cancer. This was a re-trial of Oken’s study of 1961.

98% reported that their general policy is to tell the patient. Two thirds of this group say that they never or very rarely make exceptions to this rule (Novack, D. et al. 1979: 898).

The policy of the physicians in 1977 was derived from hospital training and medical school teaching, whereas in Oken’s study of 1961, clinical experience was the major policy determinant / reason for the physicians.

### **Research into patient’s attitudes concerning truth-telling**

In terms of patients’ attitudes towards terminal disease, there were four major research projects in the West before the 1970s. In 1949, a study was conducted by W. Kelly et al. with 200 patients at the Outpatient Department of the University Hospitals at the University of Minnesota, USA. They were divided into two groups. The 100 cancer patients of one group were all interviewed personally, whereas the other 100 non-cancer patients of the other group were asked to fill in the questions, apart from some patients who were personally interviewed. The results from the 100 cancer patients are tabulated in the table below.

Questions from 1 to 4	Answers of 100 cancer patients
Question 1. Is this the first time you knew about having cancer? Yes___ No___.	85 had previous knowledge of cancer, but 15 did not.
Question 2. If you knew previously, when and how did you learn?	40 were told by local physician, 33 told at the University Hospitals, 5 told by chance by friends, etc. and 7 told at another hospital.
Question 3. Doctors and patients' relatives are occasionally inclined to believe they are protecting patients from worry by not telling them they have cancer. Do you agree? Yes___ No___	Regarding Self: 89 preferred to know cancer. 6 were rather not. 5 were indefinite.  ----- On Telling People in General: 73 think People should be told. 4 think People not to be told. 3 think Indefinite. 20 believe it depends on the individual.
Question 4. Patients with cancer are frequently cured by treatment but never find out they had cancer. It would probably help in the fight against cancer if these people knew their condition and could help to alert others to the possibility of cancer as well as offer encouragement about having it cured. Do you agree? Yes___ No___.	94 agree, 3 Disagree, 3 Indefinite.

The results for the 100 non-cancer patients are recorded in the table below.

Questions 1 and 2	Answers of 100 non-cancer patients
Question 1. If our examinations should disclose that you have a cancer, would you want to know about it? Yes___ No___	82 want to be told. 14 do not want to be told. 4 were Indefinite.
Question 2. Patients with cancer are frequently cured by treatment but never find out they had cancer. It would probably help in the fight against cancer if these people knew their condition and could help to alert others to the possibility of cancer as well as offer encouragement about having it cured. Do you agree? Yes___ No___.	88 agree. 3 disagree. 9 were Indefinite.

Please notice that two questions above have almost the same meanings: Question 3 to cancer patients and Question 1 to non-cancer patients, although the nuance of these questions is different, due to the crafting of the wording. Question 4 to cancer patients and Question 2 to non-cancer patients are exactly the same question. I wonder why the rather passive wording of



Question 3 to the cancer patients might be intentionally used because of the kind of evidence anticipated as the outcome of this study. The answer to this question comes from the statement confirming the cancer patients' self-awareness and conscientiousness of cancer versus those of non-cancer patients.

It is interesting to note that whereas 89 per cent of the cancer patients said they preferred knowing their condition, of this same group only 73 per cent thought that people in general should be uniformly told. This would seem to imply that they feel others somewhat less capable of bearing the truth or more prone to emotional shock than themselves. Another interesting point is in regard to the wording of Question 3 in the cancer patients' form, which would tend to suggest a yes answer to the patient, whereas the answers obtained were almost overwhelmingly no (Kelly, W. et al. 1950: 825).

I can also confirm that, even in the 1940s, cancer patients were prone to be more open-minded to help other people learn about cancer, given the outcome of this study with 94% of cancer patients vs. 88% of non-cancer patients strongly supporting a campaign against cancer which was considered the most notorious illness for suddenly consuming one's life.

In 1956, a study based on questionnaires sent to 560 persons was made in Wisconsin, USA. For instance, the answer to the question of "Do you think that public cancer education helps save lives?" was "Yes" for 547 vs. "No" for 9. This question vividly demonstrates that cancer was the synonym of death even in the 1950s' USA.

The answer to the question, "Does public cancer education help people to have a diagnosis made earlier on their case?" was "Yes" for 520 vs. "No" for 18. The relationship between early diagnosis and public cancer education is targeted in this question. And the need for public cancer education is certainly confirmed.

The answer to the question, "Does public cancer education help lessen the fear of cancer by explaining about it?" was "Yes" for 499 vs. "No" for 31. Mitigating the fear of cancer is seemingly the key to the education of cancer to the general public. Here I wonder if asking the persons of their daily habits/customs might also help them become aware of and/or look at their own routines reflectively in terms of cancer.

The answer to the question, "Do you know more about cancer than your parents?" was "Yes" for 468 vs. "No" for 78. This clearly shows ordinary persons become more interested in cancer than previous generations.

The answer to the question, "Does public cancer education clear up the question of whether cancer is curable or not?" was "Yes" for 465 vs. "No" for 54.

The answer to the question, “If a patient has cancer, should he or she be told this fact?” was “Yes” for 451 vs. “No” for 66. Many who didn’t answer left a question mark, checked yes and no, or qualified their not answering by a comment. Thus, eighty percent of respondents of the total of 560 individuals want to be told if they have cancer (Samp, R. and Curreri, A. 1957: 383 – 384). Here, I wonder what would differ if the above question had been asked with “you” (directly asking the person), not in the third party “he/she”. A revised question, “If you have cancer, would you like to know the fact of cancer?” would make a difference to the outcome.

The policy of the University of Wisconsin Cancer Research Hospital was to tell the patient of cancer, except where the family disagreed. Or, a sympathetic physician was expected to discuss the entire description of the patient’s condition with the patient and the family in order to better manage their feelings. Regarding a sympathetic physician, what feature would be needed for such physician in the 21<sup>st</sup> century?

In 1960, a study of 101 Inoperable Cancer Patients was executed in Lund, Sweden. The 101 inoperable cancer patients were broken down into: 43 stomach cancer patients; 22 colon cancer patients; 12 rectum cancer patients; 9 liver cancer patients; 5 pancreas cancer patients; and 10 other cancer patients. Concerning life expectancy, 42 patients died within 3 months, 25 patients died within 6 months, 25 patients died within 12 months, 7 patients died more than 12 months later, and 2 patients were listed unknown.

Among the 38 patients whose cancer was told by the surgeon, 33 patients positively accepted cancer and seemingly recognised their prognosis. Thus, “it is not easy to hide the truth, and their anxious observation of the surgeon and nurses may confirm their suspicion” (Gerle, B. et al. 1960: 1210).

The individual patient’s difference of how the truth is told is stated by B. Meyer between never telling truth as not to harm and quickly telling cancer (1958: 209f.). Thus, the Lund study verifies the context-oriented cancer-telling and cancer vs. life expectancy in Sweden in 1960.

In 1963, a study of “Activities of Daily Living” was conducted in Cleveland, USA, with 1001 patients on the application of the “Index of Independence in Activities of Daily Living” (Index of ADL) to observe elderly and chronically ill patients. This index, with the classifications of bathing, dressing, going to toilet, dependent, transfer, continence, and feeding, is a tool “in the study of prognosis and the effects of treatment ... as an objective guide in clinical practice... and as a means for gaining more knowledge about the aging process” (Katz, S. et al. 1963: 919).

The trial and outcome of this study are very helpful to obtain the reflections of elderly and chronically ill patients regarding their daily activities. Here, I must stress the importance of daily activities for everyone, strictly speaking to those vulnerable patients. Daily activities are the key to avoiding cancer diagnosis to be told by physicians, because an onset of cancer would hardly become on the next day the deadly serious cancer, as cancer diagnosis is the result of the accumulation of the patient's bad habits/activities in his/her everyday life. When cancer is found at an early stage, treatment is more likely to be successful.

#### **4. The Dignity of the human being and patient autonomy emerge as core values to affect truth-telling in medical practice**

From the foregoing discussion, we can see that medical truth-telling becomes more highly valued as best practice as the twentieth century progresses. The factors that make truth-telling really important came from outside the medical community. These include the recognition of the inherent dignity of the human person, and the respect due to the decision-making capacities of the person, as an autonomous subject with best interests and preferences. The change of socio-cultural factors in the West functioned to enable individual human beings to be regarded as worthwhile and to be treated as equal. In reality, the transition that took place in the West, from no-truth-telling to truth-telling, is not unrelated to the development of Western society in terms of how to equally value any human being in everyday life. The ripple effect of such social change in the West was then exported worldwide. These would give rise to patient-centred medical practice.

Along with the Bible as the overture of welcoming in an all-inclusive society, we can point to the influence in the West of philosophers such as Descartes (1596 – 1650) who recognises the self as the creature of conscientious thinking (Taylor, C. 1991: 25), and Kant (1724 – 1804) who created the idea of the self-determination of choices (Faden, R. and Beauchamp, T. 1986: 237 – 262) and the rational-human-being highly respected. According to John Stuart Mill, “the only freedom which deserves the name, is that of pursuing our own good in our own way, so long as we do not attempt to deprive others of theirs, or impede their efforts to obtain it” (Mill, J. 1998: 17). This statement of John Stuart Mill is closely connected to the meaning of autonomy used by ordinary people today (Meulenbergs, T. and Schotsmans, P. 2005: 124 – 125). Autonomy in modern human society means self-desires actualized in context.

Crucially, the concept of human dignity became incorporated into the Universal Declaration of Human Rights by the United Nations on the 10<sup>th</sup> of December in 1948 in its first article.

Article 1. All human beings are born free and equal in dignity and rights. They are endowed with reason and conscience and should act towards one another in a spirit of brotherhood.

Thus, many countries' constitutions incorporate the dignity of human beings as a human rights standard. Concerning the human rights movement which influenced how to treat patients in the USA, American pioneers of the human rights movement began their actions after the dignity of human beings was globally recognized by the United Nations in 1948. However, other socio-cultural factors also played a part in the transformation towards patient-centred medical care. I would argue that the shift towards the practice of truth-telling between physician and patient can never be fully grasped, unless the socio-cultural changes of American society are thoroughly digested, based on the Civil Rights Movement of Dr. Martin Luther King, Jr. followed by the consumer protection and humanitarian movement organized by Ralph Nader from the 1970s. Thus, I believe that the move towards greater truth-telling is a product and/or side-effect of the human rights and consumer rights movements in the USA which directly and/or indirectly affect all other parts of the world. I also believe that the engine to replace medical paternalism with patient-centered medical treatment has come from the individual conscientious patients in the USA who began to demand patient autonomy in relation to truth-telling from physician to patient. Respect for patient autonomy made the patient's decision the number one priority in the choice of treatment based on truth-telling by the physician; this facilitated the realisation of patient centered medical treatment balanced with the quality of daily life of the patient at the end of life.

I agree with Regina Ammicht-Quinn who argued the term "human dignity" needs unpacking, as debate is expected in its practice (Ammicht-Quinn, R. 2003: 39). Whenever "human dignity" is expected to be executed in truth-telling, all persons involved in patient-physician relationships have to face the unsolved assignment of how to actualize "human dignity" to the specific patient. While some regard human dignity as a fundamental principle of respect for persons, others believe the term is vacuous. The following are arguments so far created: Ronald Dworkin highlights the interconnection among human dignity driven meanings by reflecting the inherent value of human life and respect for human life, a sense of self-identity acquired over time, and one's capacity for self-respect (Dworkin, R. 1993: 221 – 238); Bagaric and Allan regard the concept of dignity as ethically empty (Bagaric, M. and Allan, J. 2006: 265 – 266) as respect for the dignity of a person is argued by both sides for and against euthanasia; and, in response to such assertions, David Kirchhoffer prefers to see component dimensions of dignity of human person reflecting a complementary duality in which the "already" and "not yet" of human dignity are both embedded (Kirchhoffer, D. 2009: 45 – 66). Paradoxically, as wisely pointed out below, human dignity becomes cherished by the persons who are in need of dignity.

it has to be said that human beings in their lack of dignity are the ones who can appeal to it, since despite their physical, psychological or moral wretchedness, or

rather precisely in it, they still bear witness to the ‘nothingness of the human condition’ and by their distress can each appeal to their human dignity (Valadier, P. 2003: 56).

Here, I wonder if the following statement of Martin Buber on who can meet God could share the key to who can discover what is missed in real human life.

If you explore the life of things and of conditioned being you come to the unfathomable, if you deny the life of things and of conditioned being you stand before nothingness, if you hallow this life you meet the living God (Buber, M. 1953. Smith, R. (trans.) *I and Thou by Martin Buber*. P. 79).

Here let me introduce the following statement of truth-telling which is important in any personal relationship.

We can be thankful that great strides have been made in the past century towards humanizing the sick room and the hospital, but there will always be an element of degradation in it as long as sensitive and self-respecting patients have reason to suspect that they are being lied to by their medical servants, no matter how kindly the motives may be. Truth-telling is essential to any personal, thou-thou, relationship; just as essential as love, *agape*, solicitude. The two go together, trust and truth; they require and presuppose each other. Paul’s phrase (Ephesians 4:15), “speaking the truth in love,” applies not only to our growth in Christ but to our growth in all relationships higher than *I-it*. (Fletcher, J. 1955: 49).

I believe that truth-telling is not the monopoly of medical practice between patient and physician, but that the truth should be told as the basis of every interaction, as equally important as love and trust; truth-telling and trust should go hand in hand. The role of trust in the physician-patient relationship will be explored in greater detail later in this thesis, especially in chapter five.

## **Conclusion to Chapter One**

In this chapter I have offered an historical overview of how truth-telling in medical practice came to be regarded as an important feature of patient care in the West. The chapter began with consideration of the Hippocratic Oath and the Bible as core texts that shape the value-systems of Western physicians up until the present time. An examination of the writings of physicians on truth-telling in medicine, allowed us to highlight the development of medical attitudes towards the concept and practice of truth-telling. This is especially seen during the course of the twentieth century. From this analysis a number of important themes emerge that will also be discussed in subsequent chapters. These include the following:

- Telling the truth involves “doing one’s best to convey to another person the impression that one has about the matter in hand” (Cabot).

- Yet, “a true *impression*, a fully drawn and properly shaded account” is admittedly “very difficult to give” (Cabot).
- Physicians should not attempt to deceive patients by minimising nature of their condition (Gisborne).
- “The technic of truth telling is sometimes difficult, perhaps more difficult than the technic of lying, but its results make it worth acquiring” (Cabot).
- “Directed listening [to lead the patient to think and talk about a definite subject] may be used to get information when we suspect that the patient has something on his mind which is causing him concern” (Cabot & Dicks).
- Physicians should offer hope and comfort to the sick (Percival).
- Though families may pressurise physicians to downplay the gravity of an illness to their patients, “most such medical lying is wrong, usually futile, and even harmful” (Alvarez).

This chapter also offered a survey of research conducted on truth-telling in medical settings from the 1920s to the 1970s. These have, in large part, emerged from hospital-based cancer care, and offer insights into the truth-telling practices of physicians and patient’s attitudes towards truth-telling about cancer. In terms of where the research took place, the US based medical settings were the most frequently used venues followed by the UK. The findings show that, for much of the century, a cancer diagnosis was regarded as a death sentence. For this reason, patients would in many cases resist presenting for treatment, and physicians would in many cases keep a cancer diagnosis from their patients (cf. Oken). By the 1970s, medical training appeared to be an influence in the trend to larger numbers of doctors communicating the truth of disease to their patients. The overwhelming majority of patients surveyed expressed a wish to know the truth about a cancer diagnosis. Some of the themes that emerge from the survey of the research that will be developed and further explored within the thesis are as follows:

- Trust and respect are necessary to foster truth-telling in the medical setting: “The patient needs a deep confidence in the physician ... Equally important is that the physician have a deep respect of the patient ... The doctor-patient relationship can be strengthened when there is mutual sharing and knowing together a painful truth” (Fitts and Ravdin).
- As Fitts and Ravdin note, “You can create distrust in the profession or bitter loss of faith in the family if deception is practiced by anyone.”

Finally, this chapter has traced the connection between the practice of truth-telling in medical settings in the West and the emerging philosophical, legal, and medical consciousness concerning

the human person as the locus of dignity and autonomy. The socio-cultural changes that were heralded by the UN Declaration of Human Rights (1948) influenced the civil rights and consumer rights movements of the latter half of the twentieth-century. These, in turn, led to a more patient-centered medical practice in the West, and the diminishment of the medical paternalism of previous eras. These themes will become important in chapters three and four when seeking understanding how Japanese culture has adapted to the practice of truth-telling in medical settings.

## **Chapter Two**

### **Tracing the growing emphasis on truth-telling and patient-centered medical care in the West**

[The focus of my discussion will be on the English-based countries of the UK & USA.]

#### **Abstract to Chapter Two**

In this chapter, I begin by discussing the new wave of patient treatment called the “hospice” movement, which originated in the UK, and palliative medicine, which emerged with the hospice movement, in order to show the development during the twentieth century of new and improved methods in the treatment of pain and in the care of patients at the end of life. These developments occurred within the wider movement to promote greater patient-centered medical care. These changes in medical practice, away from paternalism and towards a greater tendency to inform patients about their disease and respect patient wishes concerning their treatment options are reflected in the literature through research studies that show this shift in emphasis. This chapter surveys the research on truth-telling medical practice and on patient wishes in relation to diagnosis, treatment, and prognosis of disease.

What is distinctly observed by the research into truth-telling in Chapter Two is the gap between (a) the concept of truth-telling and (b) the practice of truth-telling which appeared as the dilemma around the discretion of the physician surely exercised depending mainly on the following two factors involved in the patient at the end of life: (1) the degree of seriousness of the disease of the patient in terms of diagnosis, treatment, and prognosis and (2) the psychology of the individual patient and/or the family. Thus, the research question of the thesis: “What do physicians tell terminal patients and/or the family of patients at the end of life with regard to the truth of diagnosis, treatment, and prognosis?” is expected intertwined with the two different kinds of psychology: (1) the psychology of the physician before and/or after the truth told and (2) the psychology of the patient and/or the family before and/or after the truth received.

This chapter also surveys the literature concerning admission of medical error, non-disclosure of information, withholding truth from patients, and physician deception. As the reason of no-truth-told, medical errors are assumed not disclosed. This leads to a variety of problems embedded in interaction between the physician and the patient and/or the family of the patient.

Along with our contemporary trend of further focusing on the patient as a whole human being, the medical literature begins to take account not only the patient’s physical health, but the patient’s mental wellbeing, and the socio-cultural-religious facets of the patient, and any other crucial problems in his or her daily life. These are often expected to be stabilized by the



interdisciplinary team of physician, nurse, social worker, psychologist, chaplain, and/or any other support staff member.

With all things duly considered, what is expected in the 21<sup>st</sup> century in terms of patient care at the end of life would help the patient at the end of life to sit at the driver's seat in order to genuinely act out the patient centered truth-telling medical practice.

Chapter Two of the thesis is to function as the continued story of truth-telling: the concept and its practice in the West in terms of diagnosis, treatment, and prognosis geared towards the patient and/or the family at the end of life up until the present day, following on from Chapter One. Now, let's begin with the influence of the hospice and palliative medicine on the understanding and practice of truth-telling.

### **1. The effect of hospice & palliative medicine on truth-telling: the concept & its practice**

Historically, so-called "palliative medicine" is originally from the hospice movement of the UK. In Japan, hospice was introduced by newspapers and books as a new medical treatment. However, how to implement hospice on the soil of Japan has been made by Japanese physicians who studied and experienced in the USA or UK regarding how to treat patients in hospice driven medical context. On hospice and palliative medicine, the UK and USA have been ahead of Japan for some decades. In what follows I will give a brief overview of the practice and principles of palliative medicine in the West.

The following statement illustrates how palliative care was considered in the 1980s, with nurses mainly involved in what was then considered the periphery of medical work:

Although housestaff in American teaching hospitals have overall responsibility for the medical care of patients, once patients are seen to be on an irreversible course toward imminent death and diagnostic or therapeutic procedures are no longer necessary, residents may withdraw from active engagement in patients' treatment. At this point other personnel, usually nurses, take over the palliative care necessary to support patients until death. Thus, once defined as dying, patients are thrust to the periphery of medical work. "Dying" becomes an exit label symbolizing patients' passages beyond the physicians' professional domain (Muller, J. and Koenig, B. 1988: 371).

Today, palliative medicine has become interwoven into hospitals on both sides of the Atlantic Ocean, as one of their core functions. Pioneer hospitals were Massachusetts General Hospital and Brigham & Women's Hospital, Boston, Massachusetts, and the Johns Hopkins Hospital in the USA. The Association for Palliative Medicine of Great Britain and Ireland was formed in 1986 and now boasts approximately 1000 medical doctors working in hospices and palliative care units in hospitals throughout the UK and Ireland. This reflects efforts to address the patient's needs

holistically, including the patient's quality of life maintained, along with pain, symptoms, and side effects certainly mitigated.

Concerning the patient with pain and suffering, the World Health Organization (WHO) created guidelines in 1980. Based on the latest guideline of the WHO, a holistic approach to the patient is the key to alleviating psychological, social, and spiritual pain as well as physical and/or symptom based pain. Thus, pain control and palliative care go together, as the shift of palliative care is recognized for many kinds of diseases.

The earlier WHO definition of palliative care stressed its relevance to patients not responsive to curative therapy. This statement might be interpreted as relegating palliative care to the last stages of care. Today, however, there is wide recognition that the principles of palliative care should be applied as early as possible in the course of any chronic, ultimately fatal illness. This change in thinking emerged from a new understanding that problems at the end of life have their origins at an earlier time in the trajectory of disease (Sepulveda, C. et al. 2002: 92).

Additionally, the WHO's definition of palliative care, on national cancer control programmes: policies and managerial guidelines, 2<sup>nd</sup> ed. Geneva: World Health Organization in 2002, includes:

- Palliative care affirms life and regards dying as a normal process.
- Palliative care intends neither to hasten nor postpone death.
- Palliative care integrates the psychological and spiritual aspects of patient care (Sepulveda, C. et al. 2002: 94).

I believe the above statements acknowledge the need to respect human life, but accept that death is eventually to come as a part of normal human life, whenever and wherever the individuals live in the human world. Palliative care aims at dealing with all facets of the patient's pain and suffering in order to consider the patient as a whole.

Here let me quote two articles that reveal the core problem of end-of-life: how to maintain the quality of the patient's daily life, when he and/or she is becoming frail and his/her own time is running out of the current human world. One, from the Canadian Medical Association, states that "compassionate palliative care, even when that shortens life, is considered good and ethical medical practice" (Sawyer, D. et al. 1993: 1466). The other, from the USA, as the responses of patients' family members, states that:

many of their loved ones spent their last 3 days of life in unnecessary pain, subjected to unwanted procedures, or 'alone and isolated.' The Institute of Medicine, among other groups, has recommended the development of more humane methods of caring for the dying, including better education and research in the specialized area of palliative care (Mariner, W. 1997: 2062).

These articles seem to urge us to deeply think of how the few days of our own end-of-life should be spent in terms of quality of life, together with quantity of pain and/or suffering against the limit of medical help.

In the UK, hospice emerged along with hospitals. St. Christopher's Hospice, the first hospice in the world, was opened in the United Kingdom in 1967 by the founder, Cicely Saunders, and her team. Cicely Saunders later spoke of the philosophy of the movement: "In the hospice movement we continue to be concerned both with the sophisticated science of our treatments and with the art of our caring, bringing competence alongside compassion" (Saunders, C. et al. 1981: 4). The hospice movement contributed to a shift in people's conventional idea of death as "the great taboo subject of our age" (Young, G. 1981: 1). The staff members at the hospice say, "we believe that when time is available for unhurried discussion most people are glad of the opportunity to express their deeper fears and to face the truth, but they may need our help in initiating such discussions" (Saunders, C. and Baines, M. 1989: 9).

In palliative care, the multidisciplinary team works to deal with all kinds of pain, i.e., physical, psycho-social, and spiritual pain. The multidisciplinary team consists of the professionals who are expected to develop mutual trust among the professions and also to have the courage to speak out when appropriate (Saunders, C. 1990: v and the following pages until p. 13). Along with the multidisciplinary team, a holistic approach to dying is favoured against treatment-at-all-costs (Dickenson, D. 2000: 256).

For quality focused patient care at the end-of-life, to compassionately communicate with the patient and the family to genuinely understand their views is essential for, i.e., giving patients choices (Arnold, R. and Egan, K. 2004: 307f.) or giving bad news to the patient (Buckley, J. 2008: 46f.). The relationship between prognosis and hope needs to be further investigated, as juxtaposed with how to tell disease to patients, together with following two comments: "the challenge for physicians is to communicate prognosis accurately without giving false hope" (Ngo-Metzger, Q. et al. 2008: 167f.), and doctors are anticipated "to present the facts in a hopeful manner" (Swanson, J. and Cooper, A. 2005: 76).

In palliative care, each patient has particular needs. In addition, it is necessary to be aware of "the *uncertain* nature of information in palliative care" (Randall, F. and Downie, R. 1996: 92). Other suggestions from Randall and Downie are: (a) not to deceive patients with false information to be told, and (b) to think of how to tell bad news to the patients in palliative care who can not simply believe very bad news and their responses are to deny it, due to probably keeping false beliefs of their disease (Randall, F. and Downie, R. 1996: 84f.).

In reality, in the UK, 90% of patients spend their final year at home with family carers who can have a break by using respite services in a specialist palliative care unit (Skilbeck, J. et al. 2005: 610). The community clinical nurse specialist (CNS) team at the hospice addresses the patient's and carer's needs (Lewis, D. and Anthony, D. 2007: 230). These services are really good not only for carers to alleviate their daily work by a break given, but also for patients to lessen their problems. However, palliative care and its services are less known by black, ethnic minority people, and the least affluent (Koffman, J. et al. 2007: 145).

Having visited many hospices in the UK and the USA, I believe that the hospice movement has transformed the dying process by focusing on the holistic care of the patient, including spiritual aspects. The current trend, however, is to implement hospice-driven functions into hospital settings under the name of "palliative medicine", like the Palliative Care Ward of X Hospital. Japanese version of palliative medicine in palliative care ward of hospital is expected to be created with the emphases of the dignity and autonomy of the individual Japanese patient, with spirituality included, like hospices of the West where chaplains of many religions are available 365 days a year, 24 hours a day to meet spiritual needs of patients. Anyway, I believe that Cicely Saunders, the founder of St. Christopher's Hospice, should never be forgotten for her great insights, with the following statement which is now a historical encounter with the founding patient just about to die.

The foundation of St. Christopher's is how we coped with that truth together ... The gift of £500 was left from him [the founding patient of the hospice, David Tasma of Warsaw with whom she met in 1947 in St. Thomas' Hospital] as 'to be a window in your home' ... (Saunders, C. et al. 1981: 4).

## **2. Change of truth-telling and its research to hearing patient's wishes and concerns**

On physician's telling truth of cancer to patient, following is an editorial in the *Lancet* of August 2, 1980.

In the past twenty years doctors have become more inclined to tell patients with cancer the truth about the diagnosis, but how far should they go? ... How can patients make sensible decisions about their life and financial affairs while in ignorance? ... The advice of the general practitioner can be helpful but usually the physician or surgeon must make up his own mind what to say. Calm, unhurried discussion, alone with the patient, is essential. It is wise to get the patient to ask questions and it is essential to go back the next day and continue the conversation ... The discussion [between the patient and the physician] should not be technical; precise or statistical statements of prognosis (which are sometimes foolishly given

without qualification) should be avoided, and hope should be maintained come what may (the Lancet, 1980: 245).

The above statement emphasizes the importance of the qualities of interaction for the good physician to create his/her own way of what & how to discuss with the unique individual patient. Historically, it can be said, “practices among nurses and doctors have shifted towards more truthful and honest disclosure about their patients’ health” (Tuckett, A. 2004: 508).

Here, I believe that truth-telling consists of many layers, although actual interaction between patient and physician is the outcome of their thought. Or, the underneath of truth-telling is to include (1) the struggle within the individual patient and physician regarding how to appropriately relate truth-telling to psycho-socio-cultural factors embedded in the truth, (2) the anxiety and consideration of how medical ethics, i.e., patient’s dignity and autonomy, should be executed through informed consent, and (3) communication driven problems and skills connected to how to go about the (1) and (2) oriented issues.

As the bottom line, disease obtained is everyone’s business, although its practice is hardly made in reality. Regarding the patient of Alzheimer’s disease, the medical doctor must straighten out in the interaction with the patient and the family of the patient “the lack of precision in both diagnosis and prognosis... The relative force of the arguments for telling and not telling the truth about this diagnosis will change as we learn more about Alzheimer’s disease, and new knowledge is likely to swing the pendulum even more decisively in favor of truth-telling” (Drickamer, M. and Lachs, M. 1992: 950). This article points out the importance of new knowledge as the impetus / motivation to boost the truth-telling to the patient.

Speaking of new knowledge embedded in the truth told, medical jargon is the problem as taken up by Dr. Ingelfinger with his concern of how much patients comprehend of what physicians say. Here, I believe there is not the mere coincidence of these two articles, (a) his comments quoted below and (b) those of the Lancet stated above, actually published in the same year of 1980, but they serve the purpose of illustrating that the time was ripe in 1980 to make the individual problems of interaction surrounded by truth-telling medical practice between patient and physician certainly opened up as a public debate, because patient-physician driven interaction is no longer a private matter, but one of societal problems needed to tackle through the discussion of all walks of life within society.

Do patients really understand medical words? We physicians certainly have problems with the principles and jargon of other skills ... All but the most medically sophisticated patients need to be informed, I suspect in nontechnical terms, and the physician who ignores this obligation is guilty of a form of arrogance (Ingelfinger, F. 1980: 1510).

Right here, the key to thoroughly executing truth-telling is its **process** actually taken by both parties, patient and physician, I believe. How should interaction between physician and patient go for patient certainly empowered and trust relationship eventually developed over truth-telling?

Effective interaction is a two-way process between listening and speaking. We need to deeply think of the other interlocutor's perspective with the question of, "Am I really understanding what the other individual is thinking right now?" I believe that the bottom line for a true understanding of any differences between the interlocutors (the listener & the speaker, or the patient & the physician in medical context) is the genuine interest of the interlocutors, the listener & the speaker, to try to obtain the other interlocutor's idea with great respect paid, without putting any colors, interpretations, and/or slants. Such candid feeling of one's real interest embedded is to naturally come out of the interlocutors and that they can catch on the spot the other's positive attitude to boost their own ideas easily exchanged. When the patient is telling the symptoms of the disease as direct experience, the physician is indirectly experiencing the direct experience of the patient. In here, what is expected by the physician is to think of the relationship between (1) what was told by the patient and (2) the physician's medical knowledge of the disease. Thus, the patient and the physician need each other to investigate the disease of the patient as a whole. In here, I can see the division of work between the patient and the physician to ascertain what kind of disease the patient has at the specific moment. In a nutshell, truth-telling is the "two-way street" between the patient and the physician about how to tackle the patient's disease through the vehicle of their mutual interaction.

How to effectively interact with others can never be acquired just overnight. This requires particular qualities in the physician, because medical education lacks interaction driven learning and/or training for physicians. Some of these qualities are discussed by Brewin: "If the doctor is to be understanding and on the same wavelength as the patient, communication must be two way" (Brewin, T. 1991: 1208).

Brewin suggests to obviously catch what is not said by the patient in order to help shape the content of communication, as stated below.

unspoken communication is probably at least as important as what is said. The doctor must not look or sound frightened. It helps if he or she has a quiet, yet strong and confident personality while being natural, warm, and friendly (Brewin, T. 1991: 1209).

The importance of communication means the subtleties dealt with between the patient and the physician, as raised by Baylis and Downie:

This explanation [the relationship between the question and the answer to clearly be explained to the patient by the physician] is particularly important when the

difference between the question asked and the question answered is subtle but significant (such as the difference between “What would you do *if you were me?*” where the physician attempts to answer the question from the patient’s perspective, and “What would you do *if it were you?*” where the response is informed by the physician’s personal and professional values) (Baylis, F. and Downie, J. 2001: 23).

Through revisiting Dr. Cabot of three classifications of truth-telling to patient from physician: diagnosis, treatment, and prognosis of patient’s disease, Surbone states: “truth emerges...from honest disclosure of diagnosis and from discussion of either treatment options and risk or prognosis” (Surbone, A. 2006: 949). Here, the level of honesty is pointed out as the crucial to the practice of truth-telling. Yes, truth is at stake without honest telling clearly observed by patient.

However, obtaining a succinct and right diagnosis of the patient is not the pure science of 100% accuracy. Furthermore, what makes an honest diagnosis even more difficult is when it relates to an inheritable condition. Here, the duty of physicians becomes centered, due to the nature of inheritable disease not only to make the family members of the patient risk, but also to be passed on to generations, as quoted below.

For the first time, two people sought to vindicate their right to know their parents’ genetic secrets. In New Jersey, Donna Safer was diagnosed with a cancerous blockage of the colon and multiple polyposis ... Ms. Safer obtained her father’s medical records and discovered that his death 26 years earlier was from the same condition for which she had just been treated. Knowing now that multiple polyposis was an inheritable condition and that early detection would have afforded an opportunity for early intervention and perhaps avoidance of the most serious consequences of her progressive disease, she and her husband sued the estate of her father’s physician, Dr. George T. Pack, for negligent failure to warn her of her genetic risk. At about the same time in Florida, Heidi Pate made a similar discovery (Olick, R. 2000: 43f.).

Given the fact that every patient is unique and worthy, the change of truth-telling to patient’s perspective, his or her concern and wish of disease, should be welcomed as fully executed at any given medical context. Here, I hope the genuine reflection of patient on his/her disease, as time goes on, is expected interwoven into the real content of interaction between patient and physician to help succinctly mould what is the latest truth of patient’s diagnosis, treatment with its alternatives, and prognosis at the end of life in particular.

## **2.1 Patient's wishes and concerns on truth-telling of diagnosis**

In terms of physician driven research on truth-telling of diagnosis, in 1984, a study was conducted based on questionnaires sent to 90 oncologists in more than 20 countries including England, Japan, and Scotland, but excluding the USA. The result showed that 90% of them reported an increase of diagnoses told to their patients with the word “cancer” as part of meeting their patients’ expectations. 68% of oncologists felt that disclosing diagnosis helped bring the positive attitudes of their patients in terms of

coping, compliance, tolerance of treatment, planning for future, communication with physicians and others, and improved prognosis ... Efforts to find the “correct” position about revealing or concealing cancer diagnosis must recognize that the language between doctor and patient is constrained by cultural norms. Communication is likely to be far less dependent upon the specific words used then upon the meaning that is conveyed by the doctor (Holland, J. et al. 1987: 151).

This study’s outcome revealed that we are all seemingly the slaves to our own cultural norms. I wonder if “cultural norms” themselves might be taken differently depending on the individual patient / physician, even to create the space of “intra-cultural differences” within medical contexts.

That hope needs to be addressed from physician to patient was observed based on the following study. In 1987 and 1988, the interviews of 51 oncologists were conducted at the teaching hospitals of Harvard Medical School. The total interviewees of 51 oncologists were broken down to 14 physicians from radiation oncology, 14 from surgical oncology, and 23 from medical oncology. Seven of the participating physicians were women. The mean age of all was 40.1. The interviews employed open-ended questions and closed questions, and took from 45 to 90 minutes. The result showed the importance of hope given to their patients:

Over 25% of these physicians are convinced that a positive attitude definitely influences the course of early stage cancer, and over 30% that it influences later stage cancers. Only 10% reported this as a reason for attempting to instill hope in their patients. Surgeons most commonly reported these views. The oncologists in our study overwhelmingly feel that a positive attitude influences patients’ illness experiences and their view of their doctors, and 88% report that they usually make an effort to encourage patients to hold optimistic attitudes (Good, M. et al. 1990: 70).

“How would hope be moulded for the quality of the individual patient’s daily life improved?”, I wonder.

That honesty should be addressed by physician to patient was observed by a study of 32 physicians by interview, USA in 1993. The venue for the one-hour interview with 32 physicians was a major



teaching hospital on the east coast of the USA. Regarding telling the truth about the diagnosis of cancer, most doctors interviewed would tell dying patients about their diagnosis. Regarding truth told on treatment and prognosis, it was stated that

More than 90% of the physicians answer that they do not withhold or sweeten some information even when they think that the information will make the patient unwilling to undergo a treatment ... In contrast, when the issue is about prognosis, many physicians try to give patients very vague information. Although 84% of the doctors think most patients know that they are dying, half of them do not explicitly tell patients that they are dying. They often give optimistic estimations and use euphemisms to describe patients' prognosis. They also tend to give patients the estimation of prognosis within a broad range, not using specific numbers or statistical data (Miyaji, N. 1993: 257).

This article can reveal the difference of truth told in terms of diagnosis, treatment, and prognosis, due mainly to the truth of prognosis to be problematic for the patient to make decisions based on what the physician said.

In 1999, on physician's perception regarding information disclosure, 120 medical residents (MRs) in Detroit, USA, were participated concerning what to tell to the patient on HIV and cancer, along with their self-completion questionnaire. The following are the major outcomes of this study:

Analysis revealed that: (1) MRs perceived greater justification (  $p < 0.0001$  ) in protecting family rights in HIV disease and patient rights (  $p < 0.0001$  ) in cancer; (2) male MRs were significantly more inclined to protect spouse / family rights (  $p < 0.01$  ) in HIV disease, when compared to female MRs; and (3) international MRs were significantly more inclined to protect spouse / family (  $p < 0.05$  ) and societal rights (  $p < 0.01$  ) in HIV disease, compared with United States MRs. Perception differences by MRs on ethics of information disclosure in HIV disease and cancer are based on MRs gender and their cultural background. It is important to document and address these attitudes during residency training (Cardozo, L. et al. 1999: 75).

This study appears to disclose no neutrality from any medical residents on how to tell the truth of the disease surrounded by the complexity of the patient's and the family's rights.

I think that no physician is an exception in terms of probably becoming a slave to one's own biological facts of being male or female as well as the cultural values of how an individual person is brought up, unless any ample recognition or conscientiousness is voluntarily raised by oneself on the factors which limit one's own thinking, attitude, and behavior. Here let me revisit my own experience in Boston, Massachusetts, USA, where I met an HIV positive female patient. I must, however, confess that the meeting made me feel stupid, because I did not know how to go about the topic of conversation between her and myself as well as whether or not it would be all right to shake hands with her.

Regarding patient driven research on truth-telling of diagnosis, in a study conducted in 1985 in the UK with 167 multiple sclerosis patients interviewed, the 83% within the total of the 167 multiple sclerosis patients favored knowing their diagnosis, whereas 13% were indifferent, and less than 4% preferred not to know the diagnosis. One thing agreed among them all was that the consultant should be in charge of disclosing the diagnosis and breaking the unpleasant news (Elian, M. and Dean, G. 1985: 27). The authors of the study concluded that the physicians should ask themselves “Can the patient stand *not* being told?” based on their interviewed results, rather than “Can the patient stand being told?” (Elian, M. and Dean, G. 1985: 28).

As against doctors’ fear of disclosure eventually creating suicide among their patients, “a review of records of suicide revealed only one case in 17 years that could be attributed to transmission of the diagnosis of cancer” (Elian, M. and Dean, G. 1985: 28).

The point of this study totally agreed by all the patients is worth to be acknowledged, since the consultant of the patient is the person only welcomed by the patients on truth-telling of diagnosis and bad news. Or, the outcome of this study is directly related to truth-telling in medical practice in any medical settings. Thus, prior to simply telling the truth to patients by whoever medical staff available in the medical team of patients, physicians and any other medical staff members are expected to ponder patients’ preference of the truth to be told.

In the winter of 1985 and 1986, ambulatory 224 adult patients with Alzheimer’s disease diagnosed and aged over 21 years old were asked to answer self-administered questionnaires, while they were waiting for their turn to obtain medical care from family practice or general internal practice in New Jersey, USA. On the patients’ wishes,

Patients’ interests in knowing should not be considered pointless. Further, because most patients want to know whether they are thought to have Alzheimer’s disease, it is possible to assume that most would not waive their right to be informed. (Erde, E. et al. 1988: 404).

This study is of help to learn what patients with Alzheimer’s disease want to know from their physicians. The venue of the study, where the individual patient is waiting to be called, is ideal, I think, for garnering patients’ honest ideas directly and naturally without setting the place and time. Truth-telling, however, would become threatening to patients, if the patients are advised to come to the traditional meeting room with conventional physicians on X day at Ypm. Thus, this article can give an opportunity for all of us to ponder what level of truth-telling would possibly be allowed even at a waiting room of hospitals.

In 1989, a pilot study of cancer diagnosis, with 55 patients interviewed at *the Mass General* (the Massachusetts General Hospital in Boston, Massachusetts, USA) offered how and where their cancer diagnosis was told, i.e., surgeons told 74% of the patients and primary care physicians told 11% of the patients; and the places of cancer told were: in traditional medical setting (42% in the physician's office, and 17% in a hospital room), by telephone for 23% of the patients, and in the recovery room for 19% of the patients. In terms of the patients' feedback, telephone and the recovery room were taken negatively compared with traditional medical settings (Lind, S. et al. 1989: 583f.).

The patients' views on their cancer diagnosis told were described:

Two thirds mentioned that the content of the telling is important and that honesty should be a key component of telling. (Eighty percent of the patients felt that physicians should tell the cancer patient everything, while 20% felt that patients should be told only as much as needed. Only one patient said that patients should be told nothing.) Slightly less than half volunteered that the affect of the physician is important, and a third said that it should be done gently, without excessive negativism (Lind, S. et al. 1989: 586).

On the above key points, "honesty" and "not too negative please", I wonder what would be the balance between honesty and not entirely negative information, given the fact that the patient and the physician might differ in their applications of such words. Additionally, this article reminds me of revisiting the time when I listened to the truth caused worries of the family of the patient hospitalized in this famous hospital, *the Mass General*, where Dr. Richard Cabot used to work.

In 1995, a study of total 9105 adult patients' decision-making at the end of life was conducted in the USA by the SUPPORT Principal Investigators to help improve end-of-life oriented decision-making on medical equipment, pain control, and dying process-related problems. The 9105 adult patients whose one or more life-threatening diagnoses had been told in five teaching hospitals in the USA, were contacted by (1) the physician who knew the patient's conditions and (2) the specially trained nurse who talked with the patient, the family of the patient, the physician, and the hospital staff on a variety of issues, i.e., preferences of treatment and care plan for the future in particular.

The conclusion of the study was to clearly address the problem of communication between the patient and the physician:

Enhancing opportunities for more patient-physician communication, although advocated as the major method for improving patient outcomes, may be inadequate to change established practices. To improve the experience of seriously ill and dying patients, greater individual and societal commitment and more proactive and forceful measures may be needed (The SUPPORT Principal Investigators, 1995: 1591).

I believe this study excellent for obtaining the patients' problems from various angles by applying the phase I and the phase II processes.

In 2000, in-depth interview of 17 cancer patients' needs in London, UK, was to reveal how frequently and how succinctly the present condition and the future perspective had been told by the physician, although all the patients wanted the basic information of diagnosis and treatment. However, the patients were anticipated to have three things: (1) faith in the expertise of the doctor; (2) hope, as the essential point to maintain the life of the patient as normal; and (3) charity towards other patients who had been given less information. The conclusion of this study goes to a suggestion to the government that "the government's cancer information strategy should attend to variations in patients' desires for information and the reasons for them" (Leydon, G. et al. 2000: 909).

What verified by this study is the needs of the patients to be heard thoroughly. Thus, I believe that the direction of further study related to truth-telling should be careful and detailed interviews with patients thereby investing the time to genuinely honour what the individual patient certainly wants to utter.

In 2001, 2331 patients on information needs were investigated at 34 hospitals in the UK by using an adaptation of Cassileth's Information Needs questionnaire. The results of this study showed that at first, 87% (2027 patients) wanted all kinds, even bad news as well as good news, of information; second, 98% (2203 patients) preferred to obtain cancer driven information of any possibility of their own illness in particular; third, patients more than 70 years old were prone to highly respect the doctor's discretion, leaving whether or not telling the details of their illness as the doctor's decision; and fourth, female patients preferred to obtain the name of their illness together with treatments & their alternative options (Jenkins, V. et al. 2001: 48).

This large study of the UK on information needs seems to tell what cancer patients of the UK really want to know. As the other side of the same coin, medical doctors are expected to grasp the individual patient's needs. I wonder if no one can miss what the physician told, regardless of the interpretation of the patient in his/her own time later on to fully digest what truth was told by the physician.

In 2001, 56 mentally competent patients' wish on information disclosure and truth-telling was asked by questionnaire in London, as shown below.

Ten Questions	Answers of 56 Patients
1. Do you know much about your illness?	Twenty-four (43%) patients stated inadequately told their illness.
2. Would you like further information?	Twenty-four (43%) patients wrote as inadequate on their illness told.
3. If a member of your family approached us to find out what was wrong with you would you like us to tell them?	Fifty (89%) allowed their doctor to tell their relatives with no prior notice to the patient.
4. Do you think we should ask you first?	Five patients accepted their relatives being told, preferably at first to be asked.
5. If something serious was wrong with you, would you want us to tell you (or someone else) or would you prefer not to know?	Forty-six (82%) wanted to know the truth of their own illness.
6. If you needed treatment or an operation, which was risky, would you want to know everything about it and decide what to do by yourself? If not who should decide?	Twenty-eight (50%) wanted to decide on their own. Ten (18%) wanted the doctor to make the decision. Seven (12.5%) wanted to decide with their family members.
7. Very occasionally patients have what is called a cardiac arrest. This means their heart stops beating. Usually we try to restart it using artificial respiration, drugs and sometimes an electric shock. Usually doctors decide what to do, but some patients prefer to decide for themselves. Would you like to make this decision? Would you like us or a family member to decide? Do you need more information before answering?	Thirty-one (55%) wanted to decide on their own whether or not CPR started, whereas, twenty-five (45%) wanted the doctor to make the decision. <u>No one</u> accepted their relatives to get involved in the decision-making of the medical treatment.
8. Some people make advance directives or living wills. Have you heard of this?	Eleven (20%) answered of living wills already heard.
9. If so, are there any such directives that you would want us to know about?	<u>One female patient</u> had already made a will of which her general practitioner had held a copy. <u>Three patients</u> who had already heard of advance directives wrote their directives as the feedback for Question 9, i.e., by saying "If I'm ever a cabbage and on a life-support machine, I would want it turned off" (Sayers, G. et al. 2001: 115). <u>Four patients</u> who had not heard of advance directives created directives, i.e., by saying "I would not want to be kept alive by a <u>breathing machine</u> " or "If my quality of life was such that I was not aware of things or was dependent, I would not want <u>further treatment</u> " or "I would not want to carry on if I was a vegetable" (Sayers, G. et al. 2001: 116).
10. Thank you for answering these questions. Do you think that discussing	All but three patients (5%) expressed helpful being asked.

these issues has been helpful to you?	<u>Some unsolicited comments</u> were: “The issues are important as doctors don’t have the right to make all the decisions”; “Doctors need to know what patients want”; “Makes me feel more human”; and “Nice to know that doctors care about what patients think” (Sayers, G. et al. 2001: 116).
---------------------------------------	---

This study verified two points. First, medical doctors in the UK, generally speaking, are highly trusted by patients at the time of making their decisions, due to the relatives of the patient omitted from making medical decisions (see the answers to the questions No. 6 and No. 7 in the above Table). Second, even in the UK, individuals are different, meaning that not all the patients wanted to make decisions on his or her own. Thus, “making a choice that a doctor, or a family member decide in place of the patient, is an alternative expression of autonomy, far removed from the paternalism that still dogs the practice of medicine” (Sayers, G. et al. 2001: 116). This sentence seemingly recommends taking a revised and/or a slightly different viewpoint of three concepts: (1) the autonomy of the patient, strictly speaking, on any treatment selected only by the patient, (2) the significant others, i.e., the medical doctor or the member of the family of the patient, to make decision for the patient, and (3) paternalism to be applied for decision made. In here, autonomy-oriented business can never happen without the patient as the key human being from the bottom line up until the final goal of any decisions being made.

Thus, I think that the patient must maintain his or her own thinking of what, how, and why to make decisions on end-of-life treatment and care, even when no death seems to come physically and mentally.

In 2008, unstructured and in-depth interviews conducted with ten cancer-already-disclosed patients in Ireland are to indirectly suggest that

Nurses and physicians should recognize the bad news trajectory as a process rather than an event. There needs to be an acknowledgement that for some people, there exists a period of suspected-knowing, which for many patients within this study, emerged before contact with healthcare professionals. What is required is suitable responsive techniques that balance managing anxiety, ensuring hope, and acknowledging the seriousness of the recipients’ concerns. For the healthcare professional, reassurance needs to be combined with responsive actions (Tobin, G. and Begley, C. 2008: E38).

On the above statement, what should be compared is process vs. event. I wonder, however, how this comparison between process and event would relate to truth-telling and bad news. Or, bad news has different degrees: for instance, from cancer as the patient’s diagnosis to death

certainly imminent as the prognosis of the patient. This means that there is always the milieu of the interpretation of any information by the patient himself/herself. And moreover, any truth of the patient's disease is, strictly speaking, always subject to change, as the time goes on, by certainly revealing that the nature of the truth is fragile.

Likewise, it is really hard to clearly differentiate between (1) what is the process and (2) what is the event, as the quantity and the quality of the truth go with the concepts of process and event. I wonder if both, process and event, would be the parts of train / chain of human thought and that X process turns to Y event and then Y event is shifted to be the process of Z event. In here, let me visit an expression in Japanese that is "Ningen no karada wa yamai no utsuwa" or ("the physical part of human being is the container of disease," as the direct translation from Japanese into English, or "Human beings are prone to catch disease easily," as the euphemism of asking Japanese people to pay attention to our own daily health to avoid illness of physically human nature). Or, physically speaking, the human being is always exposed to any disease. With that in mind, I think that we all should not be surprised if anything bad physically happens out of the blue. Thus, even the process of telling the truth of cancer, dying, and/or death would be equivalent to the event, I think.

In Europe, two studies of truth-telling were made: (1) 260 Gastroenterologists in 1991 and (2) 504 Physicians in 1998, as explained below. On truth-telling, 260 gastroenterologists in Europe in 1991 were asked in questionnaires about obligations and autonomy of patient, because there has been a conflict within two kinds of responsibilities of medical doctors in clinical practice: (a) the obligation to keep the Hippocratic Oath and (b) the duty to maintain the autonomy of the patient. Different tendencies are observed among medical doctors of Europe on telling the truth to their patients. For medical doctors in northern Europe, their responsibility is to tell the patient the truth to create no conflict between the Hippocratic obligation and the autonomy of the patient, whereas those of southern and eastern Europe are not to tell the patient the truth (Thomsen, O. et al. 1993: 475).

I believe that this study is helpful to raise awareness of the different attitude and behavior of medical doctors within Europe regarding how telling the truth is executed, together with the value systems of the medical doctors on what is the best for their patients.

In 1998, on how much truth was told, 504 Physicians were investigated from 16 European countries. The different climates of medical practice throughout Europe were reported below.

The Netherlands and Scandinavia generally accepted oral requests for procedures, while Germany and the United Kingdom preferred written requests ... Conclusions: Doctors are often not completely honest with their patients regarding their diagnosis or prognosis ... However, most doctors will respect a patient's right to refuse treatment (Vincent, J. 1998: 1251).

What interests me though is that both the UK and Germany share a similar medical practice around the written form to probably reveal so-called "document driven communication" to avoid problems at any given time.

## **2.2 Patient's wishes and concerns on truth-telling of treatment and its options**

A big difference of our contemporary medical practice, as compared with that of the past, is that the patient can now have choices of medical treatment in the West in particular. Thus, the content of discussion over the patient's treatment is very important, and directly connected to an atmosphere of trust between physician and patient. How far is the decision about treatment as the responsibility of the patient? Are there monetary concerns, for example, that remove certain treatment options from the table? Do medical doctors have the responsibility to lay out all the treatment options or only those that stand a realistic chance of success, or just to tell the treatment within the budget of the health provider or patient? Does the doctor communicate with the patient or with the family members or both about treatment and its alternatives? How and who would be able to make the decisions of withdrawing and/or withholding both, medical treatments and medical equipments? These are some of the core issues that have been raised concerning communicating with patients about treatment and its options. Another important area for physicians to consider is how to effectively inform patients of the risks and side effects of treatment and its alternatives.

Some thinkers urge UK physicians to follow the steps taken by their American counterparts with regard to accurate disclosure of information about side effects of any treatment and its options:

Side effects can be a good deal higher and yet, previously, oncologists may not have chosen to burden their patients with these details and ensured they truly understood them for the purposes of giving consent. Perhaps they should do so in the future, although this is a bigger step towards a North American style informed consent doctrine than most doctors in this country [the UK] would be happy to take (Paterson, I. 1994: 180).

The above statement is interesting to acknowledge the opposite flow of medical information between the USA and the UK. Regarding medical history across the pond, the



Atlantic Ocean, the UK driven information of medical ethics was exported to the USA. This time, however, the medical practice of informed consent is to be exported to the UK from its originated country of the USA.

In 2008, Off-Protocol Therapy (OPRx) driven study was conducted with 146 oncologists. The question, “How do oncologists deal with Off-Protocol Therapy (OPRx)?”, tells problem or

a dilemma emerges ... when a drug is still undergoing evaluation in clinical trials for a given indication, but is simultaneously available for off-label use. We term such use off-protocol therapy (OPRx) (Peppercorn, J. et al. 2008: 5994).

The 146 oncologists participated in this study, the Off-Protocol Therapy, were a random sample of the oncologists in the USA in 2008. This study seems to have hit on an area not commonly investigated so far.

One hundred forty-six (31%) of 471 oncologists responded. Ninety-three percent reported ever discussing and 81% ever prescribing OPRx ... While 61% of oncologists believed that patients should be discouraged from OPRx, only 31% felt it should not be available. With regard to trial recruitment, 53% felt that informed consent requires discussion of OPRx, 34% disagree, and 26% feel that patients should be provided OPRx on request, while 56% disagree. There was lack of consensus on access to OPRx in scenarios based on open trials at the time of the survey, such as adjuvant trastuzumab which 41% would provide, 59% would not. Conclusion. US oncologists report common discussion and use of OPRx, but attitudes and practices may vary substantially. There is need for greater debate regarding OPRx in oncology, further definition of the ethical and clinical issues at stake, and development of guidelines in this area (Peppercorn, J. et al. 2008: 5994).

I believe that the lack of consensus is the important finding of this study, right after investing the time for what is going on in practices and attitudes around OPRx among American oncologists. If physicians cannot figure out what the best treatment or therapy is, I wonder what content would be told by physicians to patients in their interaction. As the related issue to this study, I wonder if relationship between (1) drug / medicine manufacturing company and (2) physician should be argued on its legitimacy related to (a) medical ethics meaning responsibility and transparency of physician on medical information and (b) truth-telling deeply embedded in the quality of informed consent between patient and physician.

In 2002, based on 219 qualitative interviews of 20 inoperable lung cancer patients and 20 advanced cardiac failure driven patients, together with their carers in the community in the UK, following are the main outcomes of services related to uncertain prognosis.

More health and social services including financial benefits were available to those with lung cancer, although they were not always used effectively. Cardiac patients

received less health, social, and palliative care services, and care was often poorly coordinated. (Murray, S. et al. 2002: page 1 of 5 in bmj.com).

Many patients with end stage chronic illnesses do not receive appropriate services because their prognosis is uncertain. (Murray, S. et al. 2002: page 4 of 5 in bmj.com).

The two important issues of the patients at the end of life are hit by one ball meaning by this study, because how much services are received and how clearly prognosis is told are closely related to each other. Thus, I think that this article can verify the lack of prognosis to cause to not enough services given to the patients at the end of life. Along with (1) end-staged chronic illnesses and (2) health, social, & palliative care services for patients' daily life, there is still room to consider the individual patient's preference on how much he or she actually wants to use such services provided. This study is to educate me about the blurred area between treatment and prognosis. Or my question would be paraphrased: "Which one of either treatment or prognosis should be blamed as to create the miss-matched problems of treatment and prognosis mentioned in this study?" In reality, any estimation of prognosis has not yet come out enough so far, even with my wishful thinking of the accuracy of prognosis is expected developed pretty soon. Thus, I put this article in this section of patient's concern and wish on treatment and its options.

In 2003, concerning how to care patients and their carers, this study of dying cancer patients and their carers, with qualitative interviews, compared the developed country of Scotland and the developing country of Kenya. The result revealed the differences in the patients' experiences of disease and resources, although a holistic care of cancer patient is expected.

Conclusions. In patients living in developed and developing countries there are differences not only on resources available for patients dying from cancer but also in their lived experience of illness. The expression of needs and how they are met in different cultural contexts can inform local assessment of needs and provide insights for initiatives in holistic cancer care (Murray, S. et al. 2003: page 1. in bmj.com).

Medical practice is context driven and that the experiences of patients and their carers juxtaposed with resources available can directly and indirectly be related to what kind of information and truth would be told to the patients from the physicians, because no one can suggest anything as medical treatment which is not available in the country. Here, my question is: "What are the criteria for the right comparison of medical practices in different countries?" This study is to educate and/or to become aware of us all that the quality and quantity of medical resource at the end of life treatment available are the key determinants for both, physician and patient, either to unfortunately limit the level of the treatment for the patient or to fortunately

exercise choices of the patient among many alternative treatments available at the end of life depending on the medical setting of the patient actually cared. Thus, truth-telling of treatment and its alternatives to patient at the end of life is certainly affected by the quality and quantity of medical resource available at the individual medical context, I believe.

In 2006, on chemotherapy driven study based on the *PubMed* from 1980 to 2005, whether or not to apply chemotherapy would be the dying patient's choice to circumvent death in any event, as quoted below.

More people are starting new chemotherapy regimens closer to death, with unintended consequences of late hospice referral and escalating costs. The available data suggest that these choices are consonant with patient desires to avoid death at any cost ... We do not know if patients will understand or accept poor prognoses or that the options are limited. We do not know if patients will integrate honest information into their decision making or if the choices will change. We have no data on how people integrate financial information into their decision making (Matsuyama, R., et al. 2006: 3495).

This study of indirectly understanding patients' ideas by the vehicle of the *PubMed* is interesting in terms of accessing the trend of the patients who participated in the studies conducted over the past years from 1980 to 2005. The study, however, reveals the limit of the results, due to no direct contact with patients. Thus, the direction of further study is anticipated to be juxtaposing the researcher's first-hand experience with the patients as the original / the primary source with the references of any other data already published as the secondary source, for grasping what the patient most highly values in between (1) the truth of the disease that the patient has already acknowledged and (2) any other truth of the patient's disease which has not yet been told to the patient as being related to the patient's treatment and its alternatives, if the patient wants to obtain the information of not yet being told, prior to his/her own decision appropriately made.

### **2.3 Patient's wishes and concerns on truth-telling of prognosis**

Of the three classifications where telling the truth is required: diagnosis, treatment, and prognosis, that of prognosis is the most difficult. For one thing, prognosis concerns not so much telling the truth, but an estimate or assessment of various factors relating to recovery or otherwise. In addition, medical doctors have often avoided telling dying patients about their prognosis in order to prevent them from feeling demoralised. Instead, medical doctors have tried to give hope to patients.

Regarding truth telling about the prognosis of disease, Tattersall states that

Truth telling in discussing prognosis is difficult and distressing for health professionals and patients/families. Fears that disclosing life expectancy may erode hope is not well supported by evidence. Improved estimates of life expectancy are feasible and proposals for disclosing uncertainty while discussing prognosis merit further investigation. Accurate prediction of survival is necessary for clinical and ethical reasons, especially in helping to avoid harm, discomfort and inappropriate interventions in vulnerable patients (Tattersall, M. 2010: 294).

The question to ask is: “How far has prognosis been developed in order to be genuinely geared towards the needs of the individual patient?” No consensus has been reached among physicians on how prognosis is assessed and communicated to patients.

In 1995, based on the research of N. Christakis in the USA, prognosis was rarely told accurately to patients by physicians for many reasons, Tension exists between (1) hope given and (2) reality told as noted: “With respect to prognosis, strain can emerge in medical practice when physicians are expected to “be honest” and “be accurate” on the one hand and to “maintain hope” on the other” (Christakis, N. 1995: 150).

Physicians’ optimistic predictions help patients change to positive thinking and active attitude in their daily life.

Physicians’ optimistic predictions reinforce patients’ fulfillment of the sick role, reinforce patients’ fulfillment of their duty to be “brave” and “active and busy” as well as their duty to return to their normal state as quickly as possible. This duty to be active is so strongly a part of the medical ethos that it even appears in circumstances wherein it might be seen as unnecessary or superfluous, for example, when physicians encourage terminally ill hospice patients to get out of bed and “do something.” Physicians’ responsibility thus extends not only to making the patients well, but also to actually helping the patients to be optimistic and, consequently, active (Christakis, N. 1995: 211).

Optimism is always to prevail.

In short ... in their prognostic pronouncements, physicians counter-balance patient pessimism and reinforce patient optimism ... Most generally, when the prognosis is both unfavorable and uncertain, optimism is communicated to patients in a way that is at once recognizant of the patient’s expectations and independent of the physician’s true assessment of the prognosis (Christakis, N. 1995: 243).

Diagnosis pessimism vs. prognosis optimism is to be addressed.

In short ... the norm regarding diagnosis suggests that there is something for physicians to do (sickness abounds) and the norm regarding prognosis suggests that there is something that physicians can do (recovery occurs). These norms support both the need for and efficacy of physicians. Diagnostic pessimism is a consequence of vigilance and prognostic optimism is a consequence of hope (Christakis, N. 1995: 257).

These differences between diagnosis and prognosis appear interesting, as diagnosis is seemingly followed by the patient's medical treatment, whereas prognosis appears hardly to offer further help, although hope is anticipated against the patient's reality.

All outcomes mentioned above help to ascertain how physicians are anticipated to behave before their patients. The unsolved problem, however, is the interaction between the patient and the physician around the truth, i.e., what to tell, how to tell, and why to tell the truth to the patient. Just like patients vary, physicians vary. Thus, when it comes to truth-telling, I wish daily clinical experience of each physician would help earn the insight into whether the patient encountered, the patient at the end of life in particular, would genuinely want to know the truth or not. Additionally, I have met many patients at the end of life whose individual problems were not solved as being measured against so-called "the socio-cultural norms of the society" in which they lived.

In 1996 and 1997, prognosis driven interviews with treatment to be followed were made with 51 physicians in Michigan, USA. On how the truth is told to patients, this research was composed of face-to-face interviews with 51 physicians in Lansing, Michigan from the fall of 1996 to the spring of 1997. Based on two different scenarios of the patient with metastatic cancer, 51 physicians were asked the following questions: "What do you usually tell the patient about the prognosis in this situation?" and "What kind of information and recommendations do you make about treatment in this situation?" (Kaplowitz, S. et al. 1999: 210).

This research revealed an optimistic prognosis given, but no precise prediction of survival period given, except for when death was just about to come. The typical utterance of the physicians to their patients was

I tell the patient that these statistics apply to the overall population. They don't tell us what any single case will be like, and they don't necessarily say what will happen to you (Kaplowitz, S. et al. 1999: 214).

Tension recognized by the physicians "between providing patients with a realistic sense of the future so that they will do what they need to in their time left and a desire to maintain the patients' hope so that they will not simply give up on life" (Kaplowitz, S. et al. 1999: 215). Prognosis is seemingly offered based on the request of the patient, as stated that "we find that if patients do

not ask for the prognosis, there is a good chance that physicians will not tell them” (Kaplowitz, S. et al. 1999: 222).

Having heard the tension of the physicians between hope and reality of the patient, I understand the difficulty of telling the truth in real medical settings. However, I wonder if the discretion of the physicians would surely surpass and/or go beyond the duty or responsibility of giving prognosis to their patients. Asking is the key to making the physician begin to tell the patient the truth. Thus, patients also have the responsibility for how to ask, I believe.

In 1998, 917 adult patients of stage III or IV non-small-cell lung cancer or colon cancer metastatic to the liver, hospitalized in five teaching hospitals in the USA, were investigated based on chart review, patient interview, and surrogate interview.

The core results of this study ranged from their findings to the suggestion for future study on the relationship between (1) the patient’s understanding his/her prognosis and (2) the patient’s treatment followed preferred.

Our findings suggest that the most fundamental medical choice patients with incurable cancer face --- the decision between life-extending therapy and comfort care --- may be highly influenced by their understanding of their prognoses ... Although our data provide compelling evidence that the cancer patients participating in this study did not have an accurate understanding of their prognoses, data were not collected that would allow us to identify what was driving these estimates. In particular, we do not know what sources of prognostic information patients used, how and whether physicians provided accurate prognostic estimates to patients, and why patients did not understand them or chose not to believe them ... But, it is important to recognize that our results describe the beliefs and preferences of only those patients who were willing to share their views with the study team and should not be generalized to the entire population ... Furthermore, patients opting for care in an academic setting may be especially interested in obtaining state-of-the-art or aggressive therapy. Future studies in different settings would be valuable in elucidating the influence of these factors on the relationship between patient perception of prognosis and treatment preferences (Weeks, J. et al. 1998: 1713).

The conundrum behind all the problems stated above is the genuine lack of communication between the patient and the physician. Or, the two parties are not on the same page of the patient’s prognosis.

This study tells that patients interpreting their own remaining life for at least 6 months would rather choose life-extending therapy than comfort care compared with other patients believing not

to live for 6 months. The patients with metastatic colon and lung cancer overestimated their survival probabilities for 6 months, whereas the prognoses of the physicians were more accurate. Those patients with their own overestimated prognoses were to go through aggressive treatment, as the result of their selecting life-extending therapy, “but controlling for known prognostic factors, their 6-month survival was no better” (Weeks, J. et al. 1998: 1709f).

Having heard that, I wonder if human understanding of any event would be human interpretation, as we are the prisoners of our own subjective and idiosyncratic thinking, not by genuinely gazing what it is as objectively as possible. Here, I can see the reason why the history of philosophy included psychology, but the time came to make psychology an independent academic study for the sake of deeply comprehending what ingredients are within human being’s feelings with ups and downs just like different temperatures of all seasons.

In 2008, the self-reports of 729 physicians on prognosis disclosure were garnered in Chicago, USA to investigate how prognosis had been told to the terminal cancer patients by the physicians specialized in cancer. The following were the major findings of the study:

Although 98% said their usual practice is to tell terminally ill patients that they will die, 48% specifically described communicating terminal prognoses to patients only when specific preferences for prognosis information were expressed. Forty-three percent said they always or usually communicate a medical estimate of time as to when death is likely to occur, and 57% reported sometimes, rarely, or never giving a time frame. Seventy-three percent said prognosis communication education was either absent or inadequate during their training, and 96% believed it should be part of cancer care training ... Most medical oncologists say they do not routinely communicate an estimated survival time to their patients (Daugherty, C. and Hlubocky, F. 2008: 5988).

This study is of help to obtain candid feedback of the physicians including (1) no routine practice of telling the remaining time to the patient and (2) a lack of medical education on prognosis communication.

## **2.4 Not telling truth of medical error, interaction problems, and etc.**

Following are other repertoires on truth-telling and/or disclosure of medical information to patient in the West. Or, the continuum of truth-telling and/or information disclosure is to include, i.e., medical errors or a lie of the disease of the patient. Here, questions go to: “What are medical errors?”, “How much do physicians tell such errors?”, “Why can physicians tell a lie?”, and any other related issues.

### **2.4.1 The sincere statement that Physicians say, “I’m sorry”, is anticipated by patients**

Ideally, medical errors are expected to be told to patients by physicians’ “I’m sorry.” Physicians are prone to make errors and mistakes in relation to diagnosis, treatment, and prognosis. However, historically there has been a reluctance to admit these errors to patients by individual medical doctors. There has also been a wider culture of covering up medical errors within the medical community. The voluntary reporting of physicians’ and other medical staff’s errors is therefore rare. Hebert et al. advise honesty of physicians in regard to admitting error:

Physicians should take the lead in disclosing error to patients and their families. They should try not to act defensively or evasively but, rather, to explain what happened in an objective and narrative way, trying to avoid reacting to the charged response that such disclosure can generate. A physician may say “I’m sorry.” Patients often appreciate this form of acknowledgment and empathy. This may help to strengthen, rather than undermine, the physician-patient relationship (Hebert, P. et al. 2001: 512).

However, the reality is usually very different. It is rare for medical errors to be told to patients and their families, and there are often no guidelines or regulations in hospitals concerning good practice in this regard.

In our experience, errors by house staff (when they are detected by an attending physician) are often managed quietly and privately. There is usually no discussion with the patient and family, who are frequently left to themselves to try to understand an adverse outcome and to obtain compensation (Finkelstein, D. et al. 1997: 332).

In research into the attitudes of medical trainees concerning the disclosure of medical error to patients, 90% of trainees hesitated to disclose medical error, as noted:

Although trainees endorsed the principle of disclosing serious errors, nearly 90% reported barriers to doing so, such as concern about patient anger, fear of litigation, and uncertainty whether the patient would want to know about the error (White, A. et al. 2008: 254).

Trainees should be educated on how to tell the truth about medical errors to the patient and for acting out so-called “transparency in communication” as being of central importance to medicine. As White states, “teaching trainees how to disclose harmful medical errors to patients will be an important step toward closing the gap between patients’ justifiable expectation that harmful errors will be disclosed to them and current practice” (White, A. et al. 2008: 255). Here, I believe that the reflection of physician to try to dig into his/her own buried and unconscious value



systems and then to find out what they are is a must to be practised on his/her daily basis at any medical setting for truth-telling to become healthy and sound process to convey disease of patient.

#### **2.4.2 Physicians' telling a lie and/or deception**

Discussions over the difference between telling a falsehood and intentionally deceiving the patient have begun to be addressed since the late 1970s in medical practice.

In 1989, the "Deception" study with 211 physicians in the USA informed us of interesting points based on questionnaire.

The answer to the question of "If I were a patient, I would expect my physician to utilize deception on my behalf" was that 74% disagreed in total (36% disagreed and 38% strongly disagree). The answer to the question of "How often do you utilize deception with patients?" was that 80% said they rarely used deception (25% said never and 55% rarely).

Self-deception of physicians was of help to themselves, as it was noted that "Physicians may benefit from self-deception, as in believing that it is too uncomfortable for dying patients to discuss end-of-life issues, when it is really too uncomfortable for themselves" (Novack, D. et al. 1989: 2984). This statement seemingly tells the psychology of physicians to assume their patients would not be comfortable to talk of dying and death. Subtleness embedded in unclear explanation of illness and not enough information given to the patient can be justified under autonomy of physician or "discretion" without pointing out what really makes the patient have the specific pain and benefit. The deception of physicians should be further investigated as to pinpoint how far the application of medical ethics might be going on.

Any lie made in the medical context turns patients away from physicians. As Benn states,

a certain important boundary has been violated when a lie is told ... They have done something quite significant when they tell a lie ... It is a more serious matter to lie than to deceive without lying, although, of course and especially in medicine, the latter is usually highly reprehensible as well (Benn, P. 2001: 134).

One case where the medical lie has been tolerated is in relation to telling seriously ill patients about the wellbeing of others close to them. An example is the case of a car driver, the only survivor of an accident, who is facing death.

If a car driver who has been in an accident and is dying asks about other family members in the car who are already dead, there is no necessity to tell him the truth.

Instead, he can be told “they are being cared for” and that the important thing right now is that he be comfortable and not in pain (Thomasma, D. 1994: 380).

I believe that this example is the most difficult application of medical ethics between telling the truth and not telling the truth.

One of the central problems with the medical lie is its role in breaking trust between the patient and the physician, which is the essence of the relationship between the patient and the physician. When the lie is eventually discovered, it can also harm the patient’s health, which can deteriorate suddenly. Psychologically speaking, any medical lie can create pain and/or suffering for the patient, as the result of the trust broken:

Once lied to, even supposedly in their own interest, people will not trust fully again. And the lie is inevitably discovered, laid bare by the powerful truths of growing weakness, steady weight loss, worsening pain, and so on (Radovsky, S. 1985: 588).

I believe what should be learned from the above statement is the need for honesty to be considered and conveyed to the patient. However, I wonder how many small and unnoticeable lies we tell in our daily conversation just to alleviate the interlocutor’s feeling. The frequency of that natural human tendency would vary ranging from the extremely ambiguous and subtle lie with words and body language, without being noticed by anyone, to a lie obviously conveyed. Likewise, no one, physicians inclusive, is immune from the attractions of direct or indirect deception. I will discuss the issue of the relationship between truth-telling and trust in more detail in Chapter 5.

### **2.4.3 Withholding truth and/or information from the psychotic patient**

Psychotic patients, the exceptions of truth to be told, are noted below:

it is wrong to lie to patients in all but life and death situations. This consensus derives from powerful arguments suggesting that either the lie will cause more harm than good or it will violate the patient’s right to make an autonomous decision ... However, in cases involving psychotic patients, these arguments lose their power (Ryan, C. et al. 1995: 76).

Thus, physicians are allowed to tell a lie to their psychotic patients. In other words, there is a difference between competent and incompetent patients in terms of the justifiability of telling a lie to patients. The constant observations of interactions with the psychotic patient are necessary to succinctly figure out any different time frames between (1) when the symptoms of mental illness are prevailing for whatever reasons and (2) when the same patient seemingly is not affected by psychotic illness even within the same day. Here I believe that the relationship between telling truth and mental illness would offer more complicated and real medical problems for physicians of

clinical practice to make any appropriate decisions of what, how, and why to tell truth to incompetent patients. When a brand new mental illness is found out, physician is expected to face many new problems about truth-telling to mental ill patient.

Here let me add my experience of a mental disease patient, Mr. X, and his physician in Boston, Massachusetts in the USA. The physician said to Mr. X's parents, "as his physician, I cannot tell the truth of Mr. X's mental disease even to you, his parents, because I want to keep the confidentiality between Mr. X and me, because I promised him not to tell his parents about the details of his mental disease." This is exactly the example of complicated problem surrounded by mentally ill patient, due to the fact that medical ethics, as principle without the real context fixed, cannot help sort out the individual mentally ill patient's idiosyncratic values, interests, and/or wishes already jumbled just like "the tangled thread" among the persons involved in the specific patient. Here, I believe that the intention of his physician and his parents is exactly the same to genuinely wish Mr. X's well-being, but the way of how to act out the intention itself has turned out to be the difference of the outcome, through revealing the conflict between his physician and his parents. Thus, I am worried about what would happen once Mr. X has faced dying and/or death all of the sudden, because of massive snow of years, 2013-2014, with unpredictable weather of the east coast of the USA, since Mr. X has been living alone separated from his parents. Now, let's discuss tendency of physician with patient who has a close tie with the family.

#### **2.4.4 Physician's telling a lie to patient at the request of the family**

What was addressed by S. Dunbar is the patient as the first priority followed by the family as the second priority, as quoted below.

The fundamental responsibility is towards his patient ... The family's interests are at best secondary considerations. This is one of the first lessons one learns as a medical ethicist in a clinical setting; another accompanying lesson is that the patient's and the family's interests do not always coincide (Dunbar, S. 1990: 85).

However, medical doctors have sometimes followed the wishes of the family members and withheld information from the patient.

What is expected for physician is either to ask patient what he/she really wants or to be honest and open to the patient. Sensitive and caring physician in terminal care can wait for the patient's utterances. Or, patient can actually choose not to accept information as an expression of the patient's autonomy. Any harm can be created under any medical practice driven interaction between the patient and the physician, as mentioned below.

Just because there is intrinsic harm in telling lies to patients does not mean that there are not harms or side-effects of being open and truthful. Learning to work with and balance these risks is part of clinical practice. So is minimising risks by clear thinking (Higgs, R. 1990: 92).

Dunbar insists that the fundamental responsibility of the physician is the patient. Thus, in this case of female cancer patient, the patient's autonomy was not respected, because the surgeon told the husband of the patient about the cancer of the patient, without the patient's consent. The case, Dunbar argued, raised issues of autonomy, beneficence, veracity, and confidentiality (Dunbar, S. 1990: 85f.). Concerning trust driven problem related to this surgeon, P. Byrne argued that the deceit of the surgeon violated the trust between the medical doctor and the patient. Medical ethics based on the principles of beneficence, autonomy, and veracity cannot help solve real problems embedded in the patient and the physician relationship, because the communication of the real medical practice should meet the needs of the specific patient (Byrne, P. 1990: 89).

In 1995, regarding autonomy and ethnicity, two hundred persons aged 65 and older within Los Angeles County, California, USA, were interviewed, involving the self-identification of ethnic backgrounds among four classifications: European-American, African-American, Korean-American, and Mexican-American. Korean-American and Mexican-American subjects tended to be more related to their families with less autonomy of the patient than European-American and African-American subjects.

The old Korean-American and Mexican-American subjects with lower socio-economic status were prone to be against truth told and medical decisions made compared with European-American and African-American subjects. The difference within each ethnic group was apparent, as "much diversity of opinion occurs not only between ethnic groups but also within each ethnic group" (Blackhall, L. et al. 1995: 825).

Family-oriented decision making should also be allowed, as stated below.

Allowing patients to choose a family-centered decision-making style does not mean abandoning our commitment to individual autonomy or its legal expression in the doctrine of informed consent. Rather, it means broadening our view of autonomy so that respect for persons includes respect for the cultural values they bring with them to the decision-making process (Blackhall, L. et al. 1995: 825).

I believe that the concept of autonomy, broadened even to include the different cultural values of the family of the patient, would be the major contribution of this article to helping the family-oriented patient to feel all right to freely depend on the ideas of the family of the patient, as opposed to "the autonomy of the patient" of the West.

In 2000, the study of information-disclosure practice was conducted with 124 physicians' responses obtained in Houston, Texas in the USA. One of the questions asked in the questionnaire was answered below, as to show the tendency of a strong bond between the patient and the family of the patient over their cultural values once truth-telling is expected properly executed:

All subjects were asked, "Are you more likely to abide by a family request if you believe that informing the patient would violate their cultural norms?" Of the 112 respondents who answered this question, 70 said yes (Anderlik, M. et al. 2000: 253).

Other points claimed by the physicians are listed below (Anderlik, M. et al. 2000: 255).

Theme	Illustration
Offer truth	I ask the patient what information is needed
Disclose if patient asks	I answer truthfully to the patient if the patient asks [about prognosis], I don't volunteer the information.
Tell the truth but present positively	I always tell my patients the truth but try to put a positive spin on things.

The physicians mentioned above can address the importance of interaction between the patient and the physician by exchanging "questions by asking to each other" in order to reach the pinpoint or to narrow down what the other interlocutor really wants to obtain through listening to what the other says. I am interested in knowing how the physician can actually put a positive spin on things whenever telling the truth to the patient. This article is worthwhile and fascinating, because of mentioning both: (1) how much to tell of prognosis and (2) the reflective feedback of the physicians in terms of truth-telling actually made. Thus, I must confess right now how it is difficult for me to rigidly separate out many articles of patients at the end of life and/or terminal patients in terms of the three kinds of truth-telling of diagnosis, treatment, and prognosis, because almost every article is prone to touch and/or sprinkle even a little bit of the three aspects of truth-telling of diagnosis, treatment, and prognosis, even though the emphasis of the article is set off at the beginning of each article.

#### **2.4.5 What patients wonder at the end of life**

Patient is not an elephant in a room, but he/she is wondering about what to utter, I believe, as shown by two studies of patients interviewed below.

In 2001, in New York, USA, semi-structured interviews with 30 patients were classified by dominant themes, i.e., the struggle between living and dying or seeking meaning in dying (Yedidia, M. and MacGregor, B. 2001: 807f.). This study is very helpful to figure out what is not yet solved by the patient at the time when life and death are deeply scrutinized.

I personally feel, however, that this kind of study might face difficult problems to quickly try to identify the patient with the specific theme based on the perspectives of the researchers. It might be said that the researcher could become the slave to and/or the prisoner of the themes themselves. Thus, to genuinely listen to what the patient says and to ponder the patient's needs are incredibly essential for any shared decision-making between the patient and the physician.

In 2005, five advanced cancer patients voluntarily agreed to have interviews with the postdoctoral fellow of the Behavioral Sciences Department in the College of Medicine at the University of Kentucky in Lexington, Kentucky in the USA. The real utterances of five advanced cancer patients are listed below (Ryan, P. 2005: 1104f.).

Joe	Rose	Frank	Jesse	Ann
“To accept the fact that you are subject to growing older and you are subject to dying ... Once you accept that fact, and I guess put it in perspective, then you can live.”	“I’m not afraid... I trust Him to the end. He says I’ll never leave you or forsake you ... God gives us what we can stand, and what we can’t stand, He don’t give us.”	“I can tell you there is not much left of me. I just feel like I am at the limit and I want to go out the best way I can... as painlessly as possible.”	“I think of all the times I’ve wasted in my life. Keep up with your age. Think young and act young because one day you won’t be able to do the things you want to do. Dying is no easy thing; there’s a lot to it.”	“I never doubt, and that is faith when you don’t doubt ... A lot of people just get so upset. But I mean, I do not get upset with it ’cause I feel like I am not alone.”

I can see the differences of the individual patients reflected by (1) the individual condition of cancer itself and (2) the personal history which generated different utterances of the present status quo. Then, I wonder what would be any other deep-seated worries of which the individual can never venture to tell any other human being even when dying approaches.

#### **2.4.6 Hope vs. truth-telling to be pondered before an interaction with patient at the end of life**

Maintaining the patient's hope is the reason frequently pointed out for the physician to withhold information from the patient.

I believe that what is important is the content of communication. However, it is also important in communication to focus on what is not being mentioned by the interlocutors. The study of unspoken signs, particularly silence and sighs of the patient and/or the family of the patient during any interaction with the physician, should be conducted by the doctor and/or medical team to figure out where the patient actually stands in relation to the family on the concrete problems. In order to serve that purpose, for the patient at the end of life to experience medical treatment in particular, Buckman offers a practical guide: listening for the patient's *buried* questions, eliciting the patient's concerns compared with those of the physician, finding out both (1) what the patient knows and (2) what the same patient wants to know, before telling any *bad* news, and helping the patient's emotions to be heard and acknowledged by the physician who then is to effectively conduct any therapeutic dialogue with the patient (Buckman, R. 1998: 141f.). Having learned from Buckman, I wonder whether there might be no difference between interaction between patient and physician and psycho-therapy between anxious patient and therapist. Thus, I wish physician to learn from the expertise of therapist par excellence.

#### **2.4.7 How physicians should change for patients at the end of life**

Telling the truth is not always simple, especially when dealing with patients receiving terminal diagnoses. Except for the real life driven experience of medical doctor meaning the physician whose family member sadly passed away, it is seemingly hard for physicians to deadily and seriously consider every individual patient's death, as if it were their own, even though one of their routines in medical settings is always to confront the life and death of the patient. Thus, they could vindicate their difficulties to fully understand what kinds of intricate elements are embedded in patients' experiences of facing death.

Concerning patients' comments on their physicians' attitudes and utterances, it is clear that medical doctors can non-verbally and often unwittingly disclose their feelings to their patients. Patients are constantly checking their physicians' attitudes. This is particularly the case when patients face any end-of-life situation, and their sensitivity is prone to reach the highest level, even with irritation, due to the saddest condition being imminent. Thus, a physician's very presence tends to provide patients with multiple interpretations, as two cancer patients have uttered:

One [doctor] was very grim, and when I saw him I would feel death was right around the corner. And then I'd talk to this other doctor and I don't think he would sugar-coat things, but when you add a little bit of hope, a little bit of positiveness... it makes you want to fight a little more... that's really, really important.

[Doctors] give you the negative and they scare the bejeezus out of you and then they expect you to go home and fight. I see people sitting in the [chemotherapy] room and they look sad and so depressed and so defeated. I don't find it in the nurses, but I find it in the doctors. And it's devastating (Curtis, J. et al. 2002: 359)

It is clear, therefore, that more needs to be done to help medical doctors become effective communicators, as Charlton notes, "medical education should facilitate the improvement of communication skills in truth disclosure" (Charlton, R.1997: 168).

In particular, medical students are often not taught how to deal with dying patients nor are they given training in communicating bad news to patients about their diagnosis, treatment & its options, and prognosis, as Fallowfield states below.

Poor training in communication skills leaves most doctors unable to give bad news appropriately ... All doctors have their individual styles ... A study has shown that medical students regard death as failure ... It has been thought that people who fear dying choose medicine as a career because the ability to control disease and save lives confers a sense of power over death (Fallowfield, L. 1993: 476 – 478).

Even in 1972, a similar point was made by Olin meaning death is timeless or old and new issue at any given time.

In fact, it often would seem that the [medical] faculties assume that the development of attitudes and skills necessary to work with a dying patient will somehow be acquired without direct instruction. What actually is acquired or reinforced in many students is an attitude that serves defensively to maintain an emotional distance between them and dying patients. This is doubly unfortunate. First, the dying patient is deprived of a needed emotional support by his student doctor when the time is long past for the usual medical/surgical therapies; second, the student's own fearful attitudes and apprehensions toward death, learned long before medical school, may be reinforced by having a remote relationship with his patient. Death then represents a medical failure to the student instead of being valued as a dignified human event (Olin, H. 1972: 564).

One of the problems physicians tend not to be able to appropriately assess the diagnosis, treatment, and prognosis of the patient is that they can hardly think of the death of the patient coming pretty soon, if the same patient can verbally communicate as natural as any other healthy persons even in medical context. Or medical doctor's assessment about the diagnosis, treatment,



and prognosis of the patient can be skewed and/or disrupted by the doctor's own interpretation of the patient's communicative ability not only in words, but also even with body language.

Individuals are known not only as patients but also as interacting human beings, a patient's capacity for interaction can influence notions of what constitutes "evidence" for continuing treatment. Moreover, it can influence when a patient is identified as dying. If patients are mentally alert and able to engage with others in their environment, physicians are more reluctant to interpret other signs as indicating a steady progression toward death. As an intern commented, "If they can laugh, they're not dying" (Muller, J. and Koenig, B. 1988: 361).

The above article tells the destructive factor, the patient's laugh, wrongly interpreted as against the patient's real status quo. Physicians need to be trained in the repertoires of body language of patients enough to analyse, i.e., laugh of the patient compared with natural laugh of healthy human beings, prior to creating any truth of the patient's diagnosis, treatment, and prognosis.

## **2.5 Interdisciplinary Team needed for Truth-telling: the concept and its practice**

The following three articles explain the contribution of an interdisciplinary team to the stabilization of patients' daily life.

In 2000, what is considered to be important for 340 seriously ill patients at the end of life was investigated in USA, as their important factors shown below.

Participants ranked freedom from pain most important and dying at home least important among 9 major attributes. Conclusions: Although pain and symptom management, communication with one's physician, preparation for death, and the opportunity to achieve a sense of completion are important to most, other factors important to quality at the end of life differ by role and by individual. Efforts to evaluate and improve patients' and families' experiences at the end of life must account for diverse perceptions of quality (Steinhauser, K. et al. 2000: 2476).

This study extends the horizon of the studies already conducted, with social workers and chaplains are included as essential witnesses and important supporters to understand the patient as a whole. Or, their perspectives of social workers and chaplains, so far considered as rather peripheral against those of the physicians and nurses, are anticipated to trigger an attitude of thinking twice, i.e., to reconsider what would be the truth created for the patient. Here, I wish to visit the idiom, "not seeing the forest for the trees" meaning whatever truth of the patient made by an interdisciplinary team of medical setting should include the patient's tangible and/or intangible aspects as much as possible in order to certainly avoid any medical doctor driven slant.

This study, with social workers and chaplains involved in identifying what are the patient's problems, has given the clues to what future study of truth-telling and information disclosure should be like, while keeping the quality of the patient's daily life right at the end of life.

In 2005 in the USA, the responses of 494 pastoral care related staff showed the chaplain as important for the patients' emotion being heard, although the discrepancy between (1) administrators' recognizing the value of chaplain and (2) many hospitals' having no chaplains on staff, remains for further investigation (Flannelly, K. et al. 2005: 87f.).

This article can verify the necessary action taken for the patient by the chaplain who is ready to listen to whatever the patient's spiritual problems are at any given time.

In 2008 in Texas, USA, the interdisciplinary team of many professionals for the patient's wellbeing, i.e., physicians, nurses, social workers, psychologists, and chaplains, was expected to tell the patient about terminal prognosis (Wittenberg-Lyles, E. et al. 2008: 2358).

The comparisons between (1) the three assumptions of current communication prescripts analyzed by Eggly, Penner, Albrecht, et al., 2006 and (2) the conclusion of this study based on the observations of the 11 terminal prognosis communication events of the in-patient geriatric palliative care team between January and May in 2006 in San Antonio, Texas, the USA, are listed below (Wittenberg-Lyles, E. et al. 2008: 2358f.).

The actual and specific three assumptions of current communication prescripts analyzed by Eggly, Penner, Albrecht, et al., 2006, listed below.	The conclusion of this study based on the observations of the 11 terminal prognosis communication events, listed below.
1. Physicians can plan bad news interactions.	The patient never heard of his terminal status before this specific visit.
2. Interactions consist of physician-patient dyad	The patient and family are the unit of care in the palliative care setting.
3. Bad news as one central piece of information.	Redundancy, i.e., to tell four times: "the tumor will not go away" is central to telling terminal prognosis to the patient.
	Current U.S. protocols of training have no family focused communication included. But palliative care teams talk to the family on the decision made on palliative and end-of-life care options. No systematic help exists for physicians to share difficult news with their patients, as currently available guidelines are instructions with the slant to physicians' training.

This study is of help to know the gap between (1) where current guidelines stand primarily geared towards physicians' training and (2) where the guideline-to-be should focus to execute patient-oriented clinical practice including truth-telling to patient.

## **2.6 Patient centered Truth-telling practice and its Research expected in the 21<sup>st</sup> century**

The following two articles were found on the lack of the truth or information told or exchanged between the patients and medical staff.

In 2006, non-disclosure of information was reported in Glasgow & Yorkshire, UK.

On what is significant for decision-making, situations of necessary information not exchanged between the patients and the health professionals during consultations were revealed as the result of this study at Grampian, Glasgow, and Yorkshire in the UK.

With 20 patients involved in this study, the interviews, with the patients and the health professionals (HP) before and after their consultations, included 26 recorded consultations and 137 associated interviews.

The results of this study showed 34 instances of non-disclosure of information on the patient's problem, as well as 52 instances of non-disclosure of information on treatment or management options. The following are the major findings:

- The details on the cause of the patient's symptoms were not exchanged on the patients' problem, as pointed out by both the patients and the HP. The consensus of both patients and the HP is that discussion is needed on what caused the patient's symptoms.
- The treatment options available were not exchanged, as pointed out by both of the patients and the HP. The consensus here is the need for options of treatment.
- The patients' reasons for not exchanging information were mainly the attitude of the physician, i.e., the patient said, "I was just put off just by his arrogance... he wasn't very friendly... it was just his manner, you know, he was just awful" (Bugge, C. et al. 2006: 2071). And also, the patients wanted to withhold information, due to their own desired goals.
- The HP's reasons for not exchanging information were based on their awareness, judgment, belief, and concern about the patients, i.e., their concern is to eventually avoid information on poor prognoses or "the limited effectiveness of treatment might deter patients from accepting treatment or reduce their hope" (Bugge, C. et al. 2006: 2073).

- On Patients' perceptions of the non-exchanged information, patients "were or may have been unaware that potentially relevant information had not been given to them" (Bugge, C. et al. 2006: 2073).

Full discussions can only make a shared understanding, as noted below.

Our study findings suggest that if either health professionals or patients refrain from full discussion of their beliefs and concerns about the patients' problem(s), they may not reach a shared understanding of the issues that need to be addressed ... Non-mention of a relevant treatment option by a health professional is already considered potentially problematic when judged against current standards of (rational) shared decision-making ... Various contextual factors need to be taken into account when considering the significance of elements of information that are or are not exchanged in consultations for the quality of decision-making and patients' experiences of health care (Bugge, C. et al. 2006: 2075f.).

The core points above are: (1) to reiterate the importance of hope given to patients, (2) to mutually understand the patient's problems by discussing the values of the patient and the HP, and (3) to consider contextual factors as significant to information given. Thus, patients and the HP are expected educated about asking each other, as "patient autonomy" being executed in medical interaction.

In 2007, this study, dealing with patients and medical staff on prognosis and end-of-life disclosure, brought together the conclusions of 46 studies examining the relationship between truth-telling on prognosis and end-of-life driven illnesses garnered from the electronic data of Medline, Embase, Cinahl, PsychINFO, and Cochrane Register of Controlled Trials covering until November, 2004.

The studies reviewed suggest that patients can discuss the topic without necessarily increasing anxiety. Furthermore, avoiding the topic can have adverse outcomes. By discussing this information sensitively, and encouraging the patient to share in decision-making, the health professional can help the patient reset goals and choose appropriate supportive treatments rather than those that are burdensome. Communications skills training may equip doctors to discuss prognostic and end-of-life issues more confidently (Hancock, K. et al. 2007: 515).

This study's outcomes indirectly tell respective medical practices. The first-hand study is expected on telling prognosis of disease around death. There is a vast area of how to exchange patients' present and future problems, as the height of the bar between problems would be blurred by doctors to meet patients' tastes. Or, autonomy driven patients face difficulties. Here, practical ethics is to come of how to ascertain the truth of the patient's disease.

As to what contour physician's role would be in the 21<sup>st</sup> century, it is expected to effectively use a variety of communication strategies transmitted synchronously and asynchronously, i.e., conversation, written e-mail text, printed matter, and more, to give maximum confidence to patients that "their physician knows everything of importance about them, no matter who that physician is" (Horwitz, L. and Detsky, A. 2011: 1129).

So-called "patient centered health information system" is recommended, with technology more developed as the vehicle of making patients easily act out, as stated that "to be truly patient centered, the technology must do more than help patients to access health information, it must also interpret data from multiple sources and serve as a tool to facilitate action" (Krist, A. and Woolf, S. 2011: 301).

To wind up the history of truth-telling in medical practice with the concentration over the last 20 century in the West, I will summarize Dr. Rothman's comments on how research subjects are chosen by American medical researchers. The shift of American medical researchers oriented research subjects was seemingly taken place around the years of the 1990s meaning in between (a) until the 1990s and (b) the years after the 1990s. Until the 1990s, American medical researchers often chose their research subjects from the poor and vulnerable in the USA. However, they began to choose their research subjects from third world countries to test out new treatments, due to the fact that AIDS was recognized as the first modern infectious disease to have hit both of developed and developing countries. Thus, Dr. Rothman urged American medical researchers not to forget the ethics of human experimentation in the past, i.e., Nuremberg's principles in 1947 and Helsinki's Declaration of the World Medical Association in 1964 (Rothman, D. 2000: 60 – 64). These history making events of ethics taken place at Nuremberg and Helsinki are expected certainly remembered as to unmistakably set the tall order and/or high standard for all of us to comply with at any given time, in any relationship, and in any context including truth-telling in medical practice duly executed.

## **Conclusion to Chapter Two**

This chapter has traced developments in the concept and practice of truth-telling in medical settings in the West from the latter part of the twentieth-century to the present time. It has done so by surveying the medical literature and research studies that discuss truth-telling in relation to diagnosis, treatment, and prognosis of disease, especially in relation to end of life care. It examined the influence of the hospice and palliative medicine on the improved care of patients at the end of life, and it identified the growing interest in patient-centered medical care.

So far, physician's telling truth of diagnosis has dominated both in clinical practice and in research, rather than telling truth of treatment and prognosis. In a nutshell, the history of truth-telling shifted from physicians' focus to patients' focus, with most recently, the emphasis is put on both, a patient's and an interdisciplinary team's viewpoints being heard to seemingly pave the way to what the contour of truth-telling in medical practice is expected in the 21<sup>st</sup> century.

In terms of truth-telling based research, no study quoted in Chapters One and Two has duplicated the same research of others. What needed is longitudinal and qualitative study of truth-telling on diagnosis, treatment, and prognosis of our contemporary diseases, i.e., cancer, at the specific place repeatedly investigated, say for 100 years, to obtain a clear understanding of any trend of truth-telling as the benchmark for any other location specific research. However, even the sporadic and randomly conducted studies quoted so far in Chapters One and Two are of help to create the map of tendencies on telling truth to patients about their own diseases in the 20<sup>th</sup> century and beyond. Ideally, however, research of any medical reality not yet considered as the serious problem not only of patients, but also of medical practice is expected to be conducted with the insight of the researcher into any forthcoming medical crisis.

To summarise, in the last fifty years in the English-speaking countries of the West, there have been qualitative and quantitative improvements in the truth being told of diagnosis, treatment, and prognosis as well as improvements to the quality of interaction between the patient and/or the family of the patient and the physician and/or medical team. In the next chapter, we will explore the effects of Japanese cultural traditions on medical practice that relates to truth-telling to patients at the end of life.

## **Chapter Three**

### **Japanese Tradition and its Impact on current medical practice in Japan**

#### **Abstract to Chapter Three**

In this chapter, I aim to outline and analyse many of the social and cultural facets of Japan. I will argue that these traditional norms and practices play a central role in shaping the culture of medical practice in Japan. These will be shown to have a major effect on the nature of the physician-patient relationship and on the way in which patients at the end of life tend to be shielded from the truth about their medical condition.

I begin with a discussion of Japanese traditional values, because no Japanese medical practices can be understood, unless Japanese traditional values are grasped. So-called “typical vertical communication”, or the “top to down” hierarchical nature of social relationships expected in Japanese traditional settings, has been vindicated for a very long time between patients and physicians, while justifying a variety of other Japanese traditional values which are directly and/or indirectly related to truth-telling in medical practice in Japan.

Historically, Japanese medical practice has been the amalgam of imported medical knowledge revised to meet Japanese patients’ needs. Recently imported medical jargons, i.e., bioethics, patient autonomy, and informed consent, are revised to suit Japanese patients, due to the rigid and core tradition of Japan: “the family” juxtaposed with Japanese paternalism.

Then, traditional attitudes to death and dying are explained with Japanese arts and tea ceremony to give an opportunity to ponder death and life. I will show that the contemporary Japanese, however, tend not to learn the lesson from such traditions of Japan on death and dying, but they rather stick to “here and now” driven daily life without thinking of what death and dying really mean.

Then, the focus will go to how palliative care and hospices have been implemented to Japan as another imported idea from the West. For patient autonomy acted out, the Japan Society for Dying with Dignity has been informing Japanese forward-thinking individuals of dignity of human being certainly applied to a patient at the end of life, with a Living Will created.

Through exploring the difference of truth-telling in medical practice among the UK, the USA, and Japan, I would argue that some cultural aspects of Japan negatively affect truth-telling driven procedure and practice in medical settings in Japan, i.e., the hierarchical aspect of Japan to avoid treating patient as equal to physician as a human being. However, there are good elements of Japanese traditions which positively contribute to good medical practice, i.e., tea ceremony to give

the participants of tea ceremony the opportunity to ponder the meaning of death with life, and “jin” to make the physician begin to treat patient as equal to physician as a human being.

Chapter Three of the thesis is to function to introduce Japan in terms of truth-telling (the concept and its practice) heavily rooted in the tradition of Japanese hierarchical society. Even though Japan, the UK, and the USA are different about socio-cultural-religious facets of their daily life derived from their respective history, I sincerely wish that getting to know Japanese problems of truth-telling of diagnosis, treatment, and prognosis of the patient at the end of life would help ponder our universal problem with the question of: How truth-telling of disease ought to be?, together with utilizing a variety of information for our physical and mental well-being in our ever shrinking contemporary world, thanks to technology so far developed in the 21<sup>st</sup> century. In a nutshell, truth-telling to patient and/or family at the end of life is everyone’s business, since nobody knows what future brings even at our next second except God who is ubiquitous and invisible, but always with you.

## **1. Japanese traditional values**

Followings are the typical traditions of Japan with the values dragged until now. However, Fukuzawa Yukichi, the enlightened critique, urged Japan to wake up to learn from the civilization of the West. Thus, the new tradition started off by Fukuzawa Yukichi has become so-called “conscientious Japanese” created until the present day of Japan.

### **1.1 The meaning of “human being”**

In Japanese, the word, “human being”, is written “in between human beings”. Thus, it acknowledges that the existence of every Japanese, human being, is in relationship with any other Japanese, human being(s) who would happen to be around the individual Japanese person. It is assumed that every Japanese person is recognized within the context of any other Japanese person(s).

“Botsu kosei”, meaning “nothing of one’s own identity is kept”, is expected in Japanese society in order to make any interaction smoothly flow with any other Japanese interlocutor(s). Hiding one’s own identity and thoughts is acted out on a daily basis among almost all Japanese people.

Thus, it is a life-long learning process to discover how to get one’s own message across with any other Japanese interlocutor(s). Customarily, Japanese people figure out “who I am” based on one’s relationship with any other Japanese, including significant other(s) and member(s) of one’s own family.



In other words, Japanese people have no solid identity to be voluntarily revealed, except through their relationship with other Japanese person(s). Thus, only the specific relationship of the individual Japanese person is always the core, target, and/or task of the Japanese person's thought and/or action safely revealed. In a nutshell, the world of the Japanese person is within the limit of that person's relationship with the other Japanese person(s) in which he/she happens to be involved.

## **1.2 The absence of individualism in Japan**

In comparison with countries of the West, in which each human being is treated as an individual person, Japan has no concept of the individual. In the West, the individual can be himself and/or herself, whereas in Japan no exceptional behaviour is allowed. This is because in Japan an individual is not valued as the individual. The people of Japan seemingly think that all Japanese are the same and must conform. Here, let me quote one of my aunts who stayed in the USA as the spouse of a Japanese medical research fellow, said to me, "the life in Japan is just like a 100 meter race, because all the runners are heading to the same goal, as you know". I believe that her insight into the Japanese characteristic is right. In terms of Japanese trait, I, however, would argue there is the hidden agenda that anything in Japan is a severe competition among Japanese individuals. Yes, Japan is a country of competition in almost all levels of the society. Or, competition is certainly embedded even in any human relationship, particularly in the event of selecting the final one as the right qualified individual who is then officially ascertained by the hierarchy of Japan, through a long painstaking tradition.

As the notorious Japanese proverb says, "The nail which stands up is hit back down", Japanese people in general do not buy the attitude of any individual who wants to behave as the unique human being. Except for some extremely conscientious Japanese helping the really needy patient and/or person, there is no such way of thinking as helping the one sheep left out of the other remaining 99 sheep as generously written in the Bible. Regarding respect for the individual human being regardless of any context, Japanese society is focused on the mass of people, not on the individual, as the tradition is skewed towards people first and each person secondary.

In Japan, there is no such idea of "unconditional love" to any human being as in the Bible, because everything always has the particular condition of the relationship with the other Japanese person(s). As the extended milieu in real daily conversation in Japan, you don't hear "Well-done!" genuinely uttered, without any relationship, to any stranger, because "Well-done!" is only used for the specific person of the special relationship.

Regardless of any country in our global village, I wonder if a child of society would be moulded only to highly value what the society expects of the appropriate everyday behaviour of a child becoming an adult. In a nutshell, we are all blind in terms of deeply understanding other countries' value systems in our ever shrinking world, thanks to the latest and worldwide information technology. Or, even computer and internet can function in both positive and negative ways, just like any pendulum swings in two different directions, because one of our contemporary global problems is various kinds of hackings which negatively affect the possibility of confidentiality duly maintained, while offsetting the benefit of internet for information exchange on a global level. Here I believe the ethics of the internet should be created worldwide, as the ethics of truth-telling in medical practice should be created on worldwide scale.

It was wisely indicated by T. Ishikawa in the 20<sup>th</sup> year of Showa (1945) with the title of “Nihon no Saiken no tameni” (“For the Restoration of Japan”) written on the 1<sup>st</sup> of October of 1945 in the Mainichi Newspaper, Tokyo, that, because of the system of education in Japan, Japanese people had not developed the concept of an individual personality or personal attribute. Here we see what is a serious problem in Japan: the lack of a concept of personal autonomy. Japanese people, however, have a strong sense of what attributes are needed to be Japanese (quoted by Iizuka, K. 1952, the 27<sup>th</sup> year of Showa: 52f.).

More than one hundred years ago, Professor Josiah Royce, with his life's work on the grave contradiction between the individual person's desire for autonomy and the concept of loyalty, had lectures in the Summer School of Harvard University in 1906 and 1907. The contents of his lectures are available in his book published in 1995. The following extract compares individualism in the USA and in Japan. It looks at the transformation of Japan through importing and learning from the advanced knowledge of the West that took place after the Edo Era when Japan closed its doors for 265 years to all but a few European countries.

I myself do not believe, in fact, that the Japanese have rightly conceived the true worth of the individual ... For Japanese loyalty has not been a mere tool for the oppressors to use ... Japanese loyalty has led, on the contrary, to a wonderful and cordial solidarity of national spirit. If it has discouraged strident self-assertion, it has not suppressed individual judgment. For the modern transformation of Japan has surely depended upon a vast development of personal ingenuity and plasticity, not only intellectual but moral. This loyalty has not made machines out of men. It has given rise to a wonderful development of individual talent. Japanese loyalty, furthermore, if indeed strongly opposed to the individualism which knows its rights rather than its duties, has expressed itself in an heroic vigor of life which the most energetic amongst those who love to assert themselves might well envy. And meanwhile this loyalty, in some at least of its representatives, has included, has

used, has elaborately trained an inner serenity of individual self-control, a spiritual peace and inner perfection which I find enviable, and which many of our own nervous wanderers upon the higher plane might find indeed restful if they could attain to it ... I do not believe that the Japanese ought to be our models. Our civilization has its own moral problems, and must meet them in its own way. But I am sure that our various partisans of ethical individualism, when they conceive that they are opponents of the spirit of loyalty, ought to consider those aspects of Japanese loyalty which most of us do indeed find enviable. This counter-instance serves to show that, at least in some measure, the various personal goods which the different ethical individualists seek, have been won, and so can be won, by means of the spirit of loyalty (Royce, J. 1995: 36 – 37).

The comments of Professor Josiah Royce show his deep understanding of the merit and demerit of the traditions of Japan compared with those of the West.

Fukuzawa Yukichi (“Fukuzawa” is his family name followed by his first name, “Yukichi”), the founder of Keio University, the oldest private university of Japan, located in Mita, Tokyo, advocated an open-door policy for Japan and the need to end the “closed Japan” of the Edo Era in order to learn from the civilization of the West. He also argued in favour of the individual Japanese person becoming an independent person, in order to advance the cause of an independent Japan.

The following two quotations get the flavour of what he promoted, based on the translation of Professor Eiichi Kiyooka of Keio University, who is one of his grandsons:

I would make myself an example. After all, the purpose of my entire work has not only been to gather young men together and give them the benefit of foreign books but to open this “closed” country of ours and bring it wholly into the light of Western civilization. For only thus may Japan become strong in the arts of both war and peace and take a place in the forefront of the progress of the world.

I was not satisfied merely to advocate it by word of mouth. I felt that I must practise it in my actual life, and that there would be no excuse if there was the least disagreement between my words and my conduct. Hence my self-discipline and my household economy so as never to be dependent on other men. At the same time I did not hesitate if I saw anything that was necessary in advancing the cause of civilization whether it met with the general approval or not (Fukuzawa, Y., Kiyooka, E. (trans.) 1960: 246 – 247) of *The Autobiography of Fukuzawa Yukichi*.

Many a time a young man returning from abroad has come to me and asserted his belief in an independent career, saying he would not think of a government post. I usually listen to his proud declaration with half credulity. And sure enough, after a while I learn that the same young man has been appointed secretary in a certain department --- sometimes he has been lucky enough to be placed in the higher office of a province.

Of course I have no business to be criticizing the choice of a man’s career, but I have the feeling that this fallacy of the Japanese people is an evidence of the

surviving influence of the Chinese teaching. To point out this fallacy to our people and lead them in the right way of modern civilization, someone must be an example. The independence of a nation springs from the independent spirit of its citizens. Our nation cannot hold its own if the old slavish spirit is so manifest among the people. I felt determined to make an example of myself whatever the consequence of my endeavor might be. If I should be the poorer for it, I should live poorer; if I chanced to make money, I should spend it as I wished. At least I would not depend upon the government or its officials (Fukuzawa, Y., Kiyooka, E. (trans.) 1960: 314) of *The Autobiography of Fukuzawa Yukichi*.

### 1.3 The nature of Japanese language and communication

The nature of the Japanese language is extremely subjective. Thus, Japanese people have no need to say “I think...” or “My idea is...,” because such expressions of “I” and “My idea” tend to be interpreted negatively by the listener, as if the speaker were extremely arrogant and selfish with excessive pride. Thus, Japanese people rather stick to indirectly telling something, which implies expecting the listener to fill in the gap between (a) what the speaker said and (b) what the speaker did not say.

I believe that any interaction among Japanese people resembles a guessing game of figuring out what is hidden and/or not yet said. Everyday life in Japan requires one to develop the skill of reading between the lines. Japanese people, generally speaking, never directly tell their important request to the interlocutor(s), because stating what is needed to the hearer(s) creates problems and causes an awkward atmosphere between the interlocutors.

In Japan, people, in almost all cases, do not try to ask any questions, those asking “Why?” in particular, to ascertain what the speaker said, because asking is interpreted as a challenge against what the speaker said, while stopping the flow of conversation. Thus, people are prone to wondering what the speaker meant to say, right after any statement is made. Here I wonder if Japanese people would not be able to just take what another Japanese has said, as the interlocutor, at face value, or if Japanese tradition of understanding is prone to be rooted in the idiosyncratic translation of both interlocutors.

The tradition of guessing the intention and meaning of the speaker is known as “sasshi” and is discussed by K. Asakura Ph.D. below.

In the Japanese medical climate, too much emphasis on patient autonomy can cause the patients to choose from information and to force their own decision. On the other hand, too much dependence on physicians and the emphasis of “sasshi” driven communication can only contribute to disregarding the quality of life of the patients anticipated to keep on their own lives. Thus, in real medical

settings, what really needs is to try to find the balance between (1) physician driven decision made and (2) patient oriented decision (Asakura, K. 2007: 40 – 41).

Also, Dr. Hoshino raised the problems which always appear in the Japanese medical context and that he published a very practical book on how to solve interaction oriented problems between physicians and/or other medical staff and patients and/or their families (see Hoshino, K. 1997).

In Japan there is hardly voluntary self-disclosure even in daily conversation among Japanese people, unless they ask and answer their problems on their own secretly, i.e., “Is the interlocutor right now in front of me a good person? Would it be safe to say something about my private matter to the present interlocutor, without following the tradition of Japan not to tell anything at all to any strangers?” This means that independent and idiosyncratic ideas are deeply buried for the sake of not creating any shameful experience with any interlocutors. Thus, the importance of transparency in communication should be learned and developed in Japan, even for the speaker and listener to agree to disagree with mutual respect. Here, I wonder if truth-telling in Japanese medical settings would be the distilled venue of transparency in communication rarely executed compared with that of the West.

#### **1.4 Japan as a hierarchical society**

In general, Japanese people customarily compare with one another within the hierarchical society. It is likely, therefore, to look down other Japanese who are seemingly of a lower rank and/or come from less advanced regions. Japanese also tend to look down on anything considered non-modern or primitive, and only admire what is interpreted as advanced. Their narrow-mindedness negatively influences how they get along with any other Japanese, because no rights are given equally to every individual, regardless of difference in situation (Miyamoto, T. 1995: 306).

#### **1.5 “Giri Ninjyo” as the core tradition of Japaneseness on how to treat others in daily life**

In contrast to the present image of Japan as a major country in the free world economy, relatively mature Japanese people primarily living in Japan still stick to the archaic human relationship called “giri” in Japanese. “Giri” is a commitment or promise and that no duty is attached, unlike a right. “Giri” makes Japanese people accept either a pseudo-parental role or a child-like role in social groups. The set term called “giri ninjyo” (“the promise and human feelings”) causes many Japanese to experience conflicts in the meaning and the application of “giri” and “ninjyo” put

together. Thus, Japanese people tend not to want any negotiation of face-to-face confrontation (Minami, H. the 28<sup>th</sup> year of Showa. (1953): 186f.).

As the latest information related to “giri ninjo”, the history-making earthquakes and tsunami which hit Japan on the 11<sup>th</sup> of March in 2011 did make many Japanese people re-think the importance of the family and “ninjo” rather than “giri”. Some Japanese medical doctors told me in 2011 that “ninjo” would become one of the important considerations, if the Japanese patient wants to highly value “ninjo”.

### **1.6 Japanese Household (“Ie”): the vital tradition with Insider vs. Outsider**

Japanese people have developed their own unique social relationship based on the Japanese household called “Ie” (Watsuji, T. 1991: 172f.). No one can exist separately from “Ie”, central importance under the tradition of the family. “Ie” defines an insider (“uchi”) or inside the household, against the outsider (“soto”) or the outside of the household. Such two divisions always function by removing outdoor shoes at the entrance of the house. For the wife, the husband is called “the person of the household” (“uchi no hito”), whereas the husband calls his wife “the insider within the household” (“kanai”). The family members are called “the persons of the household” (“uchi no mono”), although separation from the outsider is clearly made. Japanese people have no concept of separation of individuals within the inside of the household, as seen that no rooms are separated by keys. Instead, dependence (“amae”) is available with responsibility among family members (Rothenberg, L. et al. 1996: 351).

The more family members need their unity, the more resistance appears to cooperate with outside of the household. Since ordinary Japanese people have no interest in public matters, they live non-co-operative to outsider-based or societal matters (Watsuji, T. 1991: 202). According to Watsuji, despite the considerable amount of Westernization of Japan, the household system of Japan called “Ie” still exists stubbornly in Japanese cities. Thus, efforts to modernise Japan through the influence of the West are not really successful, because the past system of “Ie” still remains (Watsuji, T. 1991: 199).

Concerning family protection within the Japanese Constitution, no specific article exists in the Constitution of Japan to succinctly state protection of the family. This is because at the time when the Constitution was being drafted, there was the urgent duty to abolish the tradition of Japanese “Ie” (“the Japanese household system”). The Constitution was anticipated not to include the family protection article so as not to perpetuate the convention of the “Ie” system. Even though the draft of the Constitution states that marriage and the family should be protected legally, the

actual Constitution makes no such mention of the family. Instead, the requirement of family protection as government policy is legally made in Japan by putting the following two Articles together: Article 25 on maintaining a physically healthy and culturally appropriate human life to refer to the obligation to duly protect the Japanese family, and Article 24 on protecting the dignity of the individual person in family life (Kinjo, K. 1986: 184 – 185).

In Japan, both, raising children and taking care of the elderly members of the family, have been considered the private responsibilities of the individual family. This would seemingly be the government policy of Japan aiming at the reduction of social welfare through justifying every family as the agent and/or the replacement of what the government should have done as the social welfare system of Japan. Thus, under the present status quo of an insufficient social welfare system in Japan, both, elderly family members' support and/care and child raising, have been put on Japanese women's shoulders (Kinjo, K. 1986: 184 – 185).

### **1.7 The family (“Kazoku”) in Japanese society**

Family bonds in Japan are strong. Japanese people have a strong tradition of respect for ancestors. Based on statistics between the 1950s and 1988, more than 66% of Japanese people answered that they respected their own ancestors. To be more specific, among people over 70 years old, regardless of gender, 93% of them respected their ancestors (Tokei Suri Kenkyujo. the 4<sup>th</sup> year of Heisei, 1992: 105f.).

“Kazoku” (“the family”) was the system interwoven in Japanese society before World War II. However, after World War II, “kaku kazoku”, the “nuclear family” of husband, wife, and child, has increased by making rare three generations: grandparents, parents, and their children, live together under the same roof. This means traditional thinking on “kazoku” (“the family”) has not been welcomed by the majority of people living in present-day Japan (Morioka, K. 1993: 108f.). This overall shift in attitude to the family appears in the practices of child adoption and caring for elderly family members.

### **1.8 The adoption of children to continue the family**

Historically, in Japan, the practice of adopting a child was common, in the case of a couple having no child of their own, in order to continue the Japanese household (“Ie”) system.

Following World War II, the “Ie” system was changed legally. Traditionally, the family system remained strong until the 1950s. However, that tradition has been changing since then with the emerging trend of no adoption.

These results are based on longitudinal studies over 4 decades: from the 1950s to the 1990s. The data of the year, 1988, revealed that more than 50% of Japanese people agreed not to adopt for the purpose of continuing the family system. Nonetheless, 28% approved of adoption for this purpose, and 15% approved depending on the individual circumstance (Tokei Suri Kenkyujo. the 4<sup>th</sup> year of Heisei, 1992: 103f.).

I believe that the adoption trend within the family system of Japan indicates how difficult it is to change the mindset of Japanese people.

### **1.9 Family care of the elderly**

In Japan, taking care of elderly parents is considered a normal duty of the family. The longitudinal survey between 1963 and 1988 on the question of “What do you think of taking care of elderly parents?” offered people’s attitudes towards such care of elderly family members in terms of a good custom or a normal duty. People considering it a good custom changed from 41.8% in 1963 to 25.1% in 1988, whereas people considering it a normal duty to be taken for granted were 44.7% in 1963 vs. 51.1% in 1988, showing the increase of the view as a duty (“Jinko Mondai Chosakai” (“The Survey of Population driven Problem”), the 63<sup>rd</sup> year of Showa, 1988: 78f.). These data revealed how deeply elderly parents were connected to the family life of Japan, not only as a good custom, but as a responsibility.

In the real Japanese context, taking care of elderly parents is primarily done by the daughter and/or daughter-in-law of the family, not by the men of the same family. This fact is at odds with the current trend of women working professionally outside the home. Thus, taking care of parents makes women to go back to their own home to carry out this duty, or perhaps burden, depending on the woman’s perspective. Increasingly, however, related to the shift from “kazoku” (“the family”) to “kaku kazoku” (“nuclear family”), surveys of parents, asking about when they become elderly, show fewer now want to be dependent on their grown-up children.

The strong emphasis on the duties and responsibilities of families towards their own members means that the social welfare system of Japan is currently under-developed compared with that of Western countries. Thus, the family has to take care of and/or to help financially support elderly parents, regardless of any sense of duty or bad human relationships that might exist (Kinjo, K. 1986: 164f.). As a result of the tradition of family-based care of the elderly, there is very little social support for elderly people in Japan. This clearly has negative consequences for those elderly people



without families of their own, i.e., male Japanese in particular, in the event that his wife has gone, he might think of the worst case scenario, suicide.

The social worker is an imported profession to Japan from the West and does not operate in the same way as in the West, because of the strong family-based cultural climate of Japan. I am extremely concerned how little Japan has developed any government-led or prefecture-oriented social service systems to help the sick and patients at the end of life in particular. Social services are scarcely available in Japan compared with many kinds of social services available in the UK and in the USA.

Historically speaking, the Japanese government strategically continued to value the traditional role of the family as the sole agent to take care of the elderly members of the family, so as to offset and/or justify the government scarcely offering social service to its people. Consequently, Japanese people have learned by now that they can never rely on whatever the government has offered. Furthermore, if people have to depend only on the government's un-satisfactory social service, Japanese people feel shame. In a nutshell, Japanese people have the feeling that no help is provided, unless their own families offer help.

In order to break the cycle of (1) the social welfare system of Japan not yet fully established and (2) the responsibility of the family vindicated in Japan up until now, Japan needs to learn the lesson of social service systems of the West to genuinely help one another even in the case of non-blood-related outsiders to the family through participating in and contributing together to such social service systems.

### **1.10 Gender and conventional gender roles in Japan**

In terms of life expectancy in Japan, as the longitudinal study indicates, in the 22<sup>nd</sup> year of Showa, 1947, the life expectancy of Japanese people was 53.96 years for women and 50.06 for men, with the gap between them of 3.9 years. Since then, life expectancy has rapidly increased in Japan with the average age of 85.59 for women, and the average age of 78.64 for men, with the gap between them of 6.95 years, based on the data of the 16<sup>th</sup> year of Heisei, 2004, from the Statistic Information Department of the Ministry of Health, Labour and Welfare of Japan (Seikatsu Joho Center, 2006: 116f.). As the result of the longevity (around 85 for women, and 78 for men), those who currently confront dying and/or death are mainly the generations born before World War II, growing up under the traditional values of the family in Japan, and having greatly contributed to stabilizing Japan, right after World War II.

Historically, people in Japan were subject to the strong gender division between male and female. This fixed structure of Japanese society has not yet been changed, although the equality of both genders was stated in the Constitution of Japan, after World War II. This means that the spirit of the Constitution on gender equality has never spread to ordinary Japanese people, especially to those born prior to World War II. Japanese men are prone to put their careers first and consider the family as secondary. They may be called “*kaisha ningen*” (“the company-driven creature”), due to their devotion to the company. “*Karoshi*” (“death caused by overworking”) is not unusual among men, as the result of the massive accumulation of their daily overtime work.

Japanese women are seemingly the product of Japanese tradition in which the male gender has been more highly regarded than the female gender. Regardless of the equality of the male and female genders declared by the new Constitution of Japan, women’s role in general is based within their family only. In Japan, women are given social status only by marriage and family. Japanese women are expected to marry. Women in Japan obtain social status first by their marriage and secondly by their family. It is only within family that a woman becomes a “visible creature” (Meguro, Y. 1987: 31).

Under such an unchanged and strong social norm, the role of women is recognized as the “*shuhu*” (the key person who has responsibility for domestic matters, i.e., to take care of her husband and child in particular). This means that girls’ education in Japan is preparation for becoming a good wife. As Meguro observes, “After reaching adulthood, women are expected to get married and become “*shuhu*”. This tendency has not changed basically even in the present-day” (Meguro, Y. 1987: 175f.). The wife is expected to maintain a good relationship with her mother-in-law. In reality, however, the relationship between the wife of the son (the-outsider-turned-insider) and the mother of the son is notoriously bad in the Japanese tradition.

The woman who ventures to work outside of the family requires courage, for she is breaking the Japanese tradition of the family in which the woman stays at home as a housewife. The working woman has to carry the double responsibilities of work and home, as a member of the staff of the company during the day and as a wife and mother with all kinds of domestic matters on her shoulders, as men do not help with anything at home.

Girls in Japan are destined to have the following names: “the daughter of Mr. X”, and then, “the wife of Mr. Y”, “the mother of her child”, “the widow of the late Mr. Y”, and finally “the mother of her child who has already grown up, right after her husband’s death”. In other words, Japanese women do not have their own name as a form of self-identity which is considered appropriate in Japanese society. The female gender is always identified socially as an attachment to a male through a biological tie. I would say that Japanese society has never been developed up to

the level in which a girl or woman must have an identity of her own, regardless of marriage and family-driven social status. I would add that in Japan there is the myth of female beauty based on women looking weak in order to be protected by their husband. Generally, a big city like Tokyo has more gender equality than more remote parts of Japan.

As an extension of this situation of Japanese women, Japanese medical doctors, who have traditionally been male, have considered the female gender rather weak and less important in comparison with males. In the event of facing death and making decisions for the patient, the male member of the family tends to be more highly respected by the medical doctor in terms of the gravity of his statements. He is likely to say what would be the final words about the patient's treatment at the end of life in particular. A single female patient with no family members would be the most miserably considered and the least regarded by medical staff members of Japan, because what is taken for granted not only by almost all Japanese people, but also by the majority of Japanese medical staff is the family as the social unit attached to the individual patient. Thus, I can see truth-telling in medical practice which can never be separated from gender driven convention in Japan.

### **1.11 The problem of importing abstract concepts to Japan**

The convention and tradition of Japan rarely have abstract, universal, ultimate, intangible, purely objective ideas, and thinking patterns. This means Japan is the country of importation of abstract, universal, and ultimate concepts from the West, such as Christianity, unconditional love, the Western concept of God, democracy, equality of all human beings, human rights, patient rights, the dignity of patients, respect for patients, informed consent, patient's autonomy, individualism, freedom, and numerous other ideas. This is because there are no equivalent vocabularies in Japan as the counterparts of the foreign words to negotiate the meaning and/or to succinctly recognize the gap between (1) the original meaning of the West and (2) the original meaning of Japan.

Thus, the applications of such imported terms are expected to make Japanese people go through either positive or negative feedback depending on the individual's value system. Or, Japan has lagged behind the West in terms of the appreciation and application of these concepts, values, and ideas, particularly those that are egalitarian in nature, because Japanese society is inherently hierarchical.

Here, let me take democracy, for instance, because Japan has not yet properly exercised the concept of democracy imported from the West, although democracy is explicitly stated in the

Constitution of Japan. Thus, there is a huge gap between the Constitution's ideal and Japan's reality.

As stated by Professor Masaaki Fukuda, Japan is a developing country in terms of democracy, because the democracy of Japan is young and full democracy has not yet been put into practice (2002: 630), just like the Japanese expression, “Eni kaita Mochi” meaning “the picture of the food”, “Mochi,” of which no one has yet tasted. Here, being a person deeply impressed by the American novel, *Democracy*, written by Henry Adams (1838 - 1918), a best seller then in the United States and England, I strongly believe that democracy is not the monopoly of politicians, but should be naturally acted out by all walks of life meaning at a grassroots level in their daily practice. Thus, truth-telling is one of the venues where democracy ought to be demonstrated.

The book by Professor Fukuda contains many very interesting charts as well as his candid opinions to show his solid knowledge of Japan in terms of Japan's imported abstract terms, such as, democracy and human rights, since World War II. However, his critique on the history and the present status quo of Japan is rather too long even in Japanese. I will, therefore, present his pivotal arguments of the two pages in Japanese (Fukuda, M. 2002: 630 – 631) with the following summary of my translation:

In order to actualize the Constitution of Japan enacted right after World War II, “tate-mae” based model is called the “Constitution driven Model.” However, in reality, Japan's Diet, Legislature, and Government bureaucracies have been monopolized for 45 years, since World War II, by the party whose doctrine carries its ultimate value in terms of economic development. Thus, the mutual checks and balance systems based on the ideal of the division of power among these three important functions have almost been paralyzed. This means that the idea of democracy expected to originally act out the decision making and problem solving in the Diet and Legislature has totally been swallowed by the ideas of economic development and maintaining and expanding already existing power. Thus, although Japan has become a super-economy-oriented country, Japan still remains as a developing country in terms of human rights. Or, the actualization of Japan's social and cultural structures based on “the Constitution driven Model,” which I stated above, has been marginal, even though there were various twists and turns in the history of Japan, up until now (Fukuda, M. 2002: 630 – 631).

Professor Fukuda is not the only one to hold this view. Another professor in Tokyo, Japan, also pointed out the characteristics of Japan earlier in 1970. Her name is Professor Chie Nakane, and her core argument is quoted below.

It is in informal systems rather than in overt cultural elements that persistent factors are to be found. The informal system, the driving force of Japanese activities, is a native Japanese brew, steeped in a unique characteristic of Japanese

culture. In the course of modernization Japan imported many western cultural elements, but these were and are always partial and segmentary and are never in the form of an operating system. It is like a language with its basic indigenous structure or grammar which has accumulated a heavy overlay of borrowed vocabulary; while the outlook of Japanese society has suffered drastic changes over the past hundred years, the basic social grammar has hardly been affected. Here is an example of industrialization and the importation of western culture not effecting changes in the basic cultural structure. This structural persistence manifests one of the distinctive characteristics of a homogeneous society built on a vertical organizational principle (Nakane, C. 1970: 149).

With these scholars' analyses of Japan in mind, I wonder how difficult it is for Japan to change to a new stage of anything. What strongly persisted without changing in the history of Japan was the decision of the top leader, i.e., Tokugawa Ieyasu, the first Shogunate, who started the Edo Era in Edo, which is nowadays called Tokyo, and was determined not to open Japan's doors, except to certain foreign countries in order to maintain "the peace of Japan" for as long as possible.

In addition, the stubbornness of Japan for not wanting any change is also rooted in the general public or grass-roots-oriented Japanese people who tend to just pick and choose any new and imported products available, as if to show their purchasing power on material goods, and to buy any new or world famous branded products.

In terms of any non-material things or abstract concepts imported from the West, individualism in particular is interpreted and put into practice only negatively, i.e., as selfishness, without grasping the original and solid concept of considering the value of the individual person as a whole. The attitude of seriously taking responsibility, for example, is totally omitted from the implantation of individualism on Japanese soil.

This means that there are at least two kinds of Japanese slant: one slant as a result of so-called "Japanese culture in general" and the other slant made by the choices of the individual Japanese person. This process of importation and enculturation of external abstract concepts into Japan always follows the same pattern of alteration within Japan. Japanese people are prone to pick and choose any foreign word depending on the context to justify their own idiosyncratic viewpoint or preference. Any imported word is peripheral in their mind, while maintaining intact their own stance of not changing.

Japan is seemingly caught between two conflicting tendencies: (a) only maintaining her own idiosyncratic tradition, attitude, and behaviour and (b) trying to change the real structure of Japan through learning from other countries. As a result, when Japanese people encounter foreign ways of thinking and acting, the following processes occur: (1) trying a copy of the foreign way of

thinking or behaving on Japanese soil; (2) experiencing the difficulties of implanting the original to Japan; (3) changing, revising, and/or adjusting the original to suit the Japanese climate; and (4) picking and choosing from the original to tailor it to the traditional Japanese way of dealing with this issue, such as, truth-telling in medical practice.

In other words, whenever any foreign concept has been imported to Japan from the West, it undergoes a variety of translations and interpretations through which the original meaning of the West disappears in order to create a so-called “Japanese friendly meaning” just like “customer friendly computer”. As we will see, in terms of medical practice for Japanese patients, any concepts imported to Japan, such as, patient autonomy and informed consent, do not carry the same meaning in Japan as in the West. Thus, I can recognize that any imported concepts are directly and/or indirectly connected to truth-telling to patients on their diseases in Japanese medical context.

## **2. Characteristics of Japanese medical practice: past and present**

That “in terms of medicine, Japan has had no originality” was mentioned when I met the professor of ethics at the famous university of Tokyo, Japan, as he continued to add, “Japan has developed her own revision based on what was learned from foreign countries with their original ideas.” These statements above are assumed to be true, along with the history of medicine in Japan is explained below.

### **2.1 The influences of foreign countries on Japanese medicine and its practice**

Foreign countries have helped shape the meaning, content, and practice of medicine throughout the medical history of Japan. The first influence was from China through Buddhism and the ideas of Confucius. The next was mainly from the Netherlands almost at the end of the 265 year Edo Era (1603 to 1867). German influence occurred from the Meiji Era of 1868 to the end of World War II, 1945, when Japan was defeated. Since Japan was occupied, right after World War II, the latest medical information has been coming mainly from the USA.

On what Japan imported from China, Ogawa explains below.

Japanese people’s daily life and their spiritual thinking have been strongly influenced by Buddhism which was introduced to Japan from China in the year of 538 ... And “Jukyo” (“Confucianism”) was also imported by China, with its two core ideas of (1) “Jin” (the word literally consists of the characters of two persons meaning the focus on the human relationship of the two persons’ existence. “Jin” is the kind and loving feeling naturally occurring in the relationship between the

persons), and (2) “Rei” (the needed concept of controlling one’s own selfishness and/or indulgence) (Ogawa, Y. 2008: 49 - 57).

In medical ethics, “Jin”, often referred to as “Medicine is Jin”, is traditionally the important concept in Japanese medical practice. “Jin” should be applied for truth-telling by Japanese physicians, because “Jin” helps to create a good interaction of truth-telling with its goal of an equal relationship between physician and patient as human beings, particularly a patient at the end of life. In reality, however, Japanese physicians have been enjoying their discretion under the so-called “paternalism” of medical practice in Japan. To point out the lack of “Jin” as the pivotal element of medical practice even in the Japanese society of his day, Kunihiko Hashida M.D. (1882 – 1945), professor of Medicine at the Imperial University of Tokyo, tells below how “Jin” should be acted out by physicians.

To include both oneself and the interlocutor means “Jin”. To become aware of the interlocutor, facing me right now as the same human being as me, is related to “Jin”. Thus, “Jin” is literally written with “two persons” and is read as “Jin”. When checking a patient’s condition, if one can examine the patient’s condition with exactly the same feeling and/or attitude as examining one’s own condition, “Jin” can exist right there. Accordingly, “Jin” is the number one essence of medicine (cited in Sekine, T. 2007: 233).

Miyasaka summarises the subsequent development of Japanese medicine and its indebtedness to Western influences:

Western Medicine and its modern medical system were implemented in Japan 100 years ago (since about the end of the Edo Era). Japanese medical history has the following two characteristics: (1) importing the excellent knowledge and technique from foreign countries ranging from China and Korea on Eastern Medicine to the Netherlands and Portugal on Western Medicine, and (2) revising the knowledge and techniques imported from foreign countries in order to suit Japanese needs and demands. However, the “sakoku” (“in Edo Era under the Tokugawa Shogunate”) stopped the introduction of Western Medicine. Then German Medicine was introduced from the Meiji Era in 1868 and continued to be imported up until the end of World War II in 1945. Right after World War II, the USA became the source of the latest medical knowledge ... The Ministry of Health and Welfare was started in 1938 (Miyasaka, M. 2005: 14).

A major way in which Western influences have affected Japanese medicine is through the implementation of bioethics. This will now be discussed in more detail.

## 2.2 Bioethics in Japan

Bioethics in Japan has not been fully developed to the extent that exists in the West. Concepts, such as autonomy, informed consent, and human dignity, have been borrowed from the West and are not yet thoroughly implanted on Japanese soil. These abstract terms continue to take a long time to be introduced, understood, digested, and diffused at grassroots levels in order to actually be used as a part of daily conversation between Japanese interlocutors.

Through acknowledging the fact in Japan that human rights of patients have not yet been developed as a Japanese social movement, Kawakami wisely points out that human rights of patients are the hidden agenda and/or *root-cause* at the basis of the imported medical practice, i.e., informed consent, from the USA. Thus, unless human rights of patients are highly valued even in Japan as the major element of the brand new medical practice of Japan, the Western original and genuine meaning of medical practice can never be completely digested followed by its full implementation in Japan, as stated below.

Informed consent and the disclosure of the patient's medical record were introduced to Japan from the USA, while Japanese physicians were showing no interest in the human rights movement, the consumer affairs movement, and citizen's movement. Thus, the problems of the application, launch, execution, and management of these new medical ideas from the USA seemingly have been confined in the Japanese medical community only. These new concepts of medical practice are expected to certainly reveal their own original and genuine meanings, once they have been united with the movement of human rights of patients (Kawakami, T. 2002: 2).

Regarding so-called "West-driven bioethics", patient autonomy is anticipated to include cultural differences, such as, between Japan and the West, as claimed by J. Okuda et al.:

The four principles of bioethics are primarily based on Western civilization and thoughts. Thus, the application of each of the four principles requires thorough investigation into how each principle relates to the cultural background and also the present status quo of the individual country. Take autonomy, for example. The principle of autonomy needs to address the difference of culture, civilization, and life style of the country in order to ascertain the gap that exists between the principle of autonomy and the common value of the community of the country. For instance, the human body and spirit are inseparable according to the value system of Japan. Thus, in Japan, it is very difficult to accept transplantation of parts of the body from the person who has died (Okuda, J. et al. 2007: 104).

Similarly, the concept of human dignity is to differ from the value system of the community, as Okuda et al. point out below:

although the dignity of the human being is the most essential concept in bioethics, the definition of the dignity of the human being is difficult, as human dignity depends on the value system of the individual community (Okuda, J. et al. 2007: 104).



In what follows I will look in more detail at the understanding of patient autonomy in Japan, and one of the barriers to its implementation, namely Japan's prevailing attitude of paternalism.

### **2.3 Patient autonomy in Japan**

From legal perspective, patient autonomy and respect for self-determination are anticipated come from the 13<sup>th</sup> Article of the Constitution of Japan. Or, as long as no any other persons are injured, autonomy means the right to freely make a decision concerning one's private business, and the freedom to seek a good life depending on the individual's own belief system (Inaba, K. 2007: 213). Here we see a huge difference between what is stated in the Constitution of Japan and what is acted out by ordinary Japanese people, particularly those at the end of life. Ironically, the life and death problems of real Japanese people have become the trigger to make Japanese people check their rights in terms of what is written in the Constitution of Japan.

The concept of patient autonomy in Japan was imported from the West. Thus, in some of the latest medical books in Japanese, the principle of patient autonomy is described as one of the four principles of bioethics of the West (i.e., Minooka, M. and Inaba, K. 2008; and Kikui, K. et al. 2008). This means there was no concept of autonomy available among Japanese people before the arrival of Western notions of autonomy in the Japanese medical context. The history of how the Western notion of patient autonomy has been introduced into the Japanese medical climate is summarised by the Japan Medical Association ("Nihon Ishikai"):

It was in the latter half of the 1960s that patient autonomy and informed consent became highly regarded to help protect patient's rights through the initiative of the USA, together with their appropriateness as legal ethics ...

These concepts were introduced to Japan in about the latter half of the 1980s. Japanese society has been learning these concepts... In a nutshell, these concepts which require the equal relationship between the physician and the patient as human beings and the wish of the patient to be respected are the opposite of the Japanese medical convention or the tradition of dealing with the patient under paternalism practiced so far. Thus, it is time to reconsider and/or change paternalism driven medical treatment. These concepts, highly regarded not only as medical ethics, but also as legal ethics, have been diffusing among physicians rapidly ...

However, these concepts are based on individualism within the democracy of the West. Thus, it is expected that a Japanese version of informed consent will be created, as Japan has a different social climate from the West. In Japan, informed consent should be considered important to establish a better human relationship and a trust relationship between the physician and the patient, even though no disagreement of patient's rights, themselves, is made ...

In Japan, it was in 1997 that informed consent, as the duty of the physician, was succinctly written in Medical Law when the revision of Medical Law was made. As mentioned above, informed consent should be understood as the important ethical duty in order to construct trust relationship and a better medical environment between the physician and the patient ("The Ethics of Physicians",

“Nihon Ishikai” (“Japan Medical Association”), 2000. In Kikui, K. et al. 2008: 156).

The above statement is very interesting, because in 2000 “Nihon Ishikai” (“Japan Medical Association”) finally accepted officially that Japan was 20 years behind compared with the West regarding patient autonomy and informed consent, which emerged in the USA as the result of the patients’ rights movement.

However, I would like to add that, strictly speaking, (1) patient autonomy and informed consent are different issues, although they are closely related, (2) patient autonomy is one of the principles of bioethics, whereas, informed consent is the application of patient autonomy in the real medical context, and (3) rather than giving a clear explanation in this statement of what patient autonomy and informed consent are all about, “informed consent” only is picked up to help develop both kinds of “relationship” of (a) human beings and (b) trust between the physician and the patient.

This kind of argument stops any further thinking of what patient autonomy really means clearly embedded in informed consent. To avoid any such confusion, the Japan Medical Association should have focused on how to understand patient autonomy as an ethical principle, rather than to point to informed consent only for the two kinds of relationship to be achieved as the end result.

In this I can see the characteristics of Japanese culture as being a “result-oriented society” rather than one where people take the time to discuss the fundamental ethics of patient autonomy. In other words, this statement seemingly acknowledges that there is no patient autonomy in Japan. What exists in Japan is only the two kinds of relationship (human relationship and trust based relationship as stated above) between the physician and the patient. Thus, any Japanese decision is created as the product of such relationship, not by respecting the individual patient’s viewpoints as the final decision, and no positive attitude was shown towards learning from so many past medical mistakes in Japan that unfortunately happened in Japanese hospitals, although this statement does admit the existence of paternalism in Japanese medical practice.

Apart from this rather late statement on patient driven medical practice by the Japan Medical Association (i.e., in 2000), enlightened Japanese physicians, such as, some with long medical practice within Japan, some who experienced clinical practice even in the West, and some with experience both in Japan and in the West, have written their own candid and brand new viewpoints in Japanese medical journals and/or in their own books since the 1980s, urging the Japanese government, their fellow Japanese physicians, and Japanese people to learn from the

West on patient autonomy and informed consent for avoiding any further delay of medical practice in Japan.

Additionally, some Japanese physicians currently in the West have been putting their comments on Japanese medical practice compared with the West on some Japanese blog sites. These physicians are brave enough to function as “whistle blowers”, in order to help Japan catch up with the West on patient rights and physician responsibility.

As Dr. Nishizawa has argued, what Japanese physicians must think right now is that “the most important thing to do is to completely secure patients’ freedom of choice. There are no other things we [Japanese medical doctors] can do, but to respect competent individuals’ own decisions” (Nishizawa, M. 2005: 22). The concept of patient autonomy is one more force transforming the tradition of medicine in Japan.

## **2.4 Japan: the Absence of patient’s autonomy with his/her own decision made**

In Japan, the idea that patients have rights to know of their illnesses in order to make their decisions at the end of life is very under-developed. Dr. Hoshino, one of Japan’s leading physicians with clinical experience both in Japan and in the West, makes the following statement regarding patient rights to be developed in Japan:

Like in Japan where the strong awareness of belonging to a group has been kept, or for Japanese people who have been raised to acquire the manner of harmony or “wa”, in Japanese, with the following two meanings: (a) to respect the opinions of the family and the close friends to be treated just like the members of the same family and (b) not to directly claim one’s own opinions and/or wishes, such attitude as making one’s own decision which seems to be rather selfish, without considering other people’s opinions, would probably not be accepted. This kind of attitude can be observed not only in people in Japan, but also people in Colombia and other South American countries where their families get together to financially help one another. The rationale, related to the following two notions: (a) the self-decision depends on the patient only and (b) even the family is not the patient, may have a negative impact on people who live with the awareness of helping one another within the family, close friends, and/or the group, because they cannot imagine the situation where no discussion could be made with their family members. Just like a saying, “When in Rome, Do as the Romans do,” in Japan, for a while, not to focus primarily on the patient’s own decision, but rather to think of both of the patient’s and the family’s decisions would be considered appropriate from the point of view of Japanese national awareness (Hoshino, K. 1996: 27).

I would argue that ordinary Japanese people have not yet matured in terms of two situations: (a) when they are healthy, they do not think of human rights or the human rights of the weak in particular; and (b) when they get sick, they only wish to recover, without pondering their own human rights as the patients, because of no prior experience of thinking of any human rights

closely connected to the options of patients at the end of life. In Japan, the typical interaction between patient and physician is for the patient to passively accept what the physician says.

In terms of patient autonomy, if Japanese people have no prior knowledge and experience of what patient autonomy means, once they have been hospitalized, how can they act as autonomous patients all of a sudden, and make their own decisions? Thus, the execution of patient autonomy is an unexpectedly high target for Japanese patients, Japanese patients at the end of life in particular, to face a so-called “double punch”: (1) their own disease treated in any unfamiliar medical settings, and (2) their own decisions created as patient autonomy executed. With these things considered, the education on patient autonomy and/or self-determination is badly needed, even when people are sound and healthy, as no one knows what future brings.

## **2.5 The family and patient autonomy**

Inside the typical Japanese family, there remains strong and mutual dependence among the family members. Just like the customary saying of “Mine is yours, while your things are my things”, so many things of the family members are overlapped and it is hard to separate them out. Thus, in terms of decisions made about patient’s medical treatment, the best way is to reach a consensus as a result of the discussion among the patient and all the members of the family. This is because the patient’s disease is important not only to the patient, but also to all the members of the family. Or, the more the patient’s disease gets serious, the more the patient’s family tends to become worried about what causes the change of the patient’s condition. The family, as the team, is to deal with the patient’s disease basically with the agreement and co-operation of all members of the family. The decision made by the agreement of all members of the family would even look like that of the patient, because the patient’s problem turns out to be the family members’, since the boundary between the patient and the members of the family of the patient is blurred, once their loved one is suffering at the end of life (Shimizu, T. 2000: 178f.).

What makes patient autonomy difficult in Japan is the inseparable relationship between the patient and the patient’s family. Thus, the concept of patient autonomy has not been learned enough by Japanese people in general.

The majority of Japanese patients hesitate or tend not to directly tell to their family members about what they really want. This means that many patients, with their genuine wishes kept secretly, are waiting for the time when their family members become aware of what the patients really want at any given time. This stems from the characteristics of Japan: non-transparency in communication. Thus, Japanese patients are the victims of this tradition of Japanese society.

Likewise, many patients' problems come from the gap of different wishes, ideas, concerns, and/or psychological pain (suffering) between the patient and the family of the patient.

Additionally, misunderstanding exists between the patient and the physician or the nurse. The lack of communication among the patient, the spouse of the patient, and medical staff hinders the patient's decision-making. For instance, the patient's wish to go back home may not be heard by the family of the patient, although the medical staff members of the hospital have already heard the wish of the patient. Or, the patient's wish of "No respirator!" was heard only by the daughter, but the same patient has not directly told such wish not only to any other members of the family, but also to the physician and any medical staff. Thus, it is terribly hard to enact patient centered medical treatment for the patients at the end of life in particular in Japan.

Even in 2013, ordinary Japanese people have not yet become aware of the importance of discussing the patient's rights related to the choice of the patient. Thus, the patient's choices at the end of life often come into conflict with the role of the family. In the West, the focus is on patient centered medical treatment, whereas in Japan, such imported idea of the patient being prioritized is somehow to be adapted to Japan. In the West, the patient's wish is highly regarded, whereas in Japan, the family of the patient has the power to ignore the patient's decision.

In Japan, along with the lack of serious debates of what the dignity of patients originally means, no one would thoroughly discuss how the patient feels in between the responsibility of the family and the burden to the family. In the West, it is not rare for the patient and the physician to begin to talk and to develop trust relationship, whereas in Japan, only minimum information is exchanged between medical doctor and patient, and there is little opportunity to genuinely develop trust relationship. Traditionally, however, Japanese patients are anticipated to blindly trust physicians under the hierarchical society.

Clearly, there are exceptions to these generalisations both in the West and in the East. Or, intra-cultural differences, i.e., the Japanese individuals with whom I met and appreciated, do exist at any given time and in any given country.

Not only Japanese patients, but also all other walks of life in Japan need to wake up to what are the needs and choices of patients at the end of life. Japanese family members, with their strong power over the patient, want to find any consensus, while ignoring what the patient said about his/her treatment at the end of life. The consensus of the family usually is taken seriously by the physician, but the family cannot always reach consensus. Dr. Asai discusses more distant family members often to ask more aggressive treatment, i.e., prolonging the patient's life as long as possible:

Family members' wishes concerning prolonging a patient's life differ. Close relatives who take care of the patient every day tend to prefer less aggressive management and a peaceful death, while other members who live far away from the hospital request us to prolong the life of the patient as long as possible (Asai, A. et al. 1997: 326).

If the physician cannot do the treatment of the patient as expected by the family, the family may begin to take legal actions against the conduct of the physician. Thus, the physician tends to become nervous about the requests of the patient's family. Dr. Asai mentions this problem in relation to advance directives, where the family's wish differs from that of the patient expressed in the living will:

It is the family that physicians must deal with after the patient dies. The fact that a physician acted upon explicit patient wishes given in an advance directive would not be enough to protect him or her from blame or a lawsuit filed by the family. Even if the law recognized the validity of patients' advance directives and granted us legal immunity, we could not avoid the agony we would feel in acting against patients' families (Asai, A. et al. 1997: 326).

According to the survey of end-of-life medical treatment in November 2001 which was actually reported in March 2002 by Life Design Institute, the research organization of Dai-Ichi Life Insurance Company, in the case of unavoidable and/or imminent death, due to incurable disease, even though the patient wants to know the stage of disease, the family does not want to let the patient know the fact, the end-of-life. This kind of family attitude, that is, "respecting the family's decisions", was supported by 21.4% of the participants. This result illustrates the strongly remaining value system of Japan meaning to respect the patient's wish to know his/her own disease is not necessarily a good idea, because the communication with the patient would probably become more difficult, once the fact of end-of-life has been informed to the patient. If the patient at the end of life wants his/her home-based care, the family members have to face dying and/or death-related problems which become their burden.

Whether physicians should tell cancer-driven changes to whom, the survey of the Ministry of Health and Welfare in Japan in 1998 is instructive:

The survey conducted by the Ministry of Health and Welfare in 1998 showed that many physicians wonder whether or not they should tell patients about the development or recurrence of cancer. More than 50% of physicians tell the facts of the patient's illness to the family of the patient first, rather than to the patient. That a family's opinions are more highly valued than the patient's own wishes is a

characteristic of Japan that is different from the Western characteristics of thinking of the family as a third person (Morioka, Y. 2001: 840).

In terms of patient autonomy, however, the physician should consider the patient's decision as the number one priority, without the physician being bothered by the patient's family members. At the same time, the patient should independently think of his/her treatment plans, without blindly following the physician's and/or the family's decisions. In Japan, the first thing to tackle is the search for how to establish respect for the patient's own decision. This should be the priority in terms of public debate in Japan (see Mitsui, M. 2003: 174).

In reality, the latest problems of treatment come from medical machines. Many Japanese families' experiences in withholding and/or withdrawing treatment have been disclosed through numerous blogs in Japanese. The main reasons why such topics have been mushrooming are: (1) the patients at the end of life may or may not be competent; (2) many families of the patients cannot figure out what would be the real wish of the patient, himself/herself; (3) the families want to control the patients' treatment without considering the patients' wish, as M. Hosaka explains, "generally speaking, there are many cases in which medical treatment of the patient is done by the family's decision, without the patient's presence" (Hosaka, M. 1993: 24); and (4) the families want to do all possible treatments for the patients, i.e., to use the latest medical technology is interpreted as the best way, because otherwise the family could be labelled as cold, and that the family is extremely cautious about any negative rumours raised on how the family members dealt with the patient.

In a nutshell, the patient's care at the end of life in Japan is stressful in order not to create and/or experience any shame based on which treatment is taken and what comes up as any thorny comments being made by the significant others in particular.

## **2.6 The tradition of paternalism in Japan**

Strong paternalism exists in Japan with the slant of Japanese traditions: (1) the hierarchical society in which medical practice is not the exception and (2) the family system of depending on all members of the family. Such paternalism is the product of Japan with "supply and demand" met for relationship between Japanese patients with their families and Japanese physicians.

The vertical interaction between patient and physician is the tradition of exchanging information between different social statuses in Japan. The patient tends to submissively wait for what the physician will say, rather than the patient himself/herself trying to say anything directly to

the physician. Most Japanese do not ask their disease driven problems to doctors because of hierarchical relationship between patient and physician. The Japanese understanding of paternalism is described below by K. Asakura Ph.D.:

Paternalism is medical treatment based on the physician's judgment and decision on the patient's interest and loss, with the premise of the physician's professional good conduct and the patient's submission. Paternalism within medicine is called "omoiyari" ("to treat the patient with kindness strongly considered") and/or "omakase" ("the patient's attitude to totally depend on the physician's orders or suggestions"), on which the mutually dependent relationship of feeling or consciousness is based (Asakura, K. 2007: 40 – 41).

Asakura Ph.D. continues:

the emphasis of "omoiyari" and/or "omakase" driven medical treatment and/or of "sasshi" driven communication is to ignore the patient's quality of life meaning to live one's own way, by not acknowledging the patient as an independent/autonomous human being (Asakura, K. 2007: 40 – 41).

Here, the pivotal questions to ask are: What is the quality of life of the patient? Who could measure it? How can the quality of patient's daily life be actualized? And then, Why? The typical way for Japanese people to try to understand what the interlocutor said, without asking the interlocutor about what he/she said to confirm the content of his/her own talk, actually leaves behind some concerns and/or worries between the interlocutors, particularly for the patient at the end of life to increasingly worry about what the physician said.

Hayashi et al. explain why physicians do not tell the truth of the disease directly to the patients and their families:

patients and families have been expected to follow doctors' decisions without questioning or little, if any, knowledge about the diagnosis and prognosis; nor did they have much access to information about the suggested treatment... Doctors decide almost everything, often without formal enquiry into patients' desire. They seldom tell the patient the true diagnosis if it has poor prospects (i.e., cancer). Doctors fear that it would make the patients depressive, cause them to give up hope, and even cause them to commit suicide (Hayashi, M. et al. 2000: 60).

Based on his thorough observations, Dr. Kashiwagi pointed out that "patients do not ask questions unless they trust medical staff [taking care of the patients]" (Kashiwagi, T. 1999: 191). In the hierarchical society of Japan, the question "Why?" is negatively taken as either a challenge or disagreement to what the interlocutor said. This is the fundamental difference between Japan and



the West where asking is welcomed to ascertain what the speaker said and then to let the interaction go further. In Japan, patients' strongly asking physicians "Why?" is not appropriate, because in hospitals where traditional or vertical Japanese interaction is expected to be maintained between patients and physicians.

The following statement by Professor Anesaki brings together some of these themes and how they play out in the current medical context of Japan:

The doctor-patient relationship in Japan is one of trust. Wordless communication, so-called 'belly talk' (*hara gei*), is a distinctive feature of personal communications in Japan and is aided by the intrinsic ambiguities of the Japanese language. Doctors tend to explain away the problem in soothing terms without necessarily providing precise information about what exactly the problem is. For the patient to ask for this information directly might be seen as questioning the doctor's knowledge, authority and judgement. To ask too many questions is as likely to bring about a rebuttal or even a refusal to carry on the consultation. Difficulties of this kind are not unknown in other countries of course, but the medical profession in Japan remains more entrenched in its views than is the case elsewhere (Powell, M. and Anesaki, M. 1990: 174).

These guessing games on whether or not matters about disease would be revealed between patients and physicians are endlessly going on in medical interaction in Japan. The trust relationship between them is expected to be constructed upon this wordless communication. Any breach of this social convention is a challenge to this unspoken but fragile trust relationship. The current situation is summarised by Ishiwata and Sakai: "Given the strong paternalism, patient passivity, and the exclusiveness among medical professionals in Japan, there is scarcely any opportunity for patients to participate in medical decision making" (Ishiwata, R. and Sakai, A. 1994: 61). To break through the paternalism is customarily not easy in Japan.

I believe this tradition of paternalism in Japan is wrong. The questions of patients should be freely asked in order to ascertain what the physician means, and in order to begin any constructive interaction based on the mutually shared medical information between patient and physician. Asakura Ph.D. has some recommendations about how paternalistic behaviour can be overcome, while communication between physician and patient is also being improved:

Thus, what is required for the physician in real communication with the patient is to think of the balance between "omakase" driven medical treatment and the patient's own decision oriented medical treatment. For example, the following strategies have been tried out: (a) telling disease is to be created to the patient, while the physician is showing his/her respect to the response of the patient, with his/her consideration of corresponding with the patient's response, and (b) on

telling a bad news, the physician should suggest some other ways as the counter-balance of the bad news in order to continuously have the hope of the patient (Asakura, K. 2007: 41).

## 2.7 Japanese medical practice of patients at the end of life: Past vs. Present

Following is a summary with some of the foregoing discussion:

Issues focused	Past	Present
Characteristics of medical practice	Paternalism. Not all truth told. Particularly no cancer diagnosis told by traditional physicians due to avoiding patients' suicide attempt as the worst case scenario.  Physician-centered medical practice.	Imported words, i.e., Informed Consent, are introduced to Japan by physicians. Thus, some physicians begin to tell truth to their patients. But, Paternalism still remains within Japanese clinical practice.  How to apply Patient centered medical practice has become thought of by some physicians.
Human relationship between the patients/their families and the physicians	Vertical relationship between the patients and the physicians based on the strong paternalism. Patients do not ask questions to physicians.	Some conscientious patients are thinking of their ways of dying, due to imported idea of the dignity of human being. Thus, some patients begin to ask the truth of disease to their physicians. Physicians have changed a bit when talking to patients and their families.
Medical Education for Japanese Physicians	To prolong patients' life as much as possible, even a minute longer.	Some teaching materials made on how to tell truth of end-of-life.
The relationship between the family of the patient and the patient	"Ie" ("household") was strong in Japan. Thus, the members of the family shared and thought of their problems of cancer and/or dying, without telling the problematic facts, i.e., cancer, to the patient.	How to relate to one another within the family is to differ depending on the individual family's conditions. The traditionalist families of physicians, however, still want to keep the paternalism of Japan.

### **3. Traditional attitudes vs. present tendency on death and dying in Japan**

Whether or not truth-telling and information disclosure are believed to help the patient at the end of life would vary according to how the society where the patient lives values the truth of disease and/or transparency in comparison with half-told truth and/or linguistic ambiguity appreciated for the sake of maintaining the patient's hope. Inevitably, the attitudes and practices of Japanese society play a part in how patients are cared for at the end of life and in decisions taken about the prolongation of life-sustaining treatment.

#### **3.1 Traditional Japanese perspectives: death is always with life**

In Japan, death is a part of life. In relation to Japanese tradition, Zeami, the founder of "Noh", argued that life can only exist with death embedded, as Yamamoto observes:

Life is always confronted with death. In other words, what makes life is to contain death in itself. If no death can be predicted and anticipated, that can never be life itself. The human being can only exist in the opposed tension between death and life within the human being himself. For example, "Zeami", the famous figure of the tradition of Japan called "Noh", created "Noh" with his insights into the twofold characteristics of human being (Yamamoto, K. Showa 56<sup>th</sup> year (1981): 342).

The relationship between death and life is expressed in the tradition of Japan through the traditional Japanese appreciation of flowers, and through the tea ceremony. The poet Saigyō, for instance, created many impressive Japanese poems that evoke death through his references to the traditional Japanese affinity with flowers. For example, Saigyō created many Japanese poems expressing worry about the falling of flowers, due to the wind in spring season. The falling of flowers captures the connection between death and life. As Yamamoto states:

Life can only be verified by death. Life retains death within life itself. Thus, death is to become the proof of life. The ancestors of Japan who deeply thought of flowers made the death/destination of flowers in exchange for the beauty of the flower as the essence of many flowers (Yamamoto, K. Showa 56<sup>th</sup> year (1981): 308).

As the tradition of Japan, the tea ceremony is rooted in pondering both, death and life, while highly appreciating the time and human relationship shared together over Japanese traditional tea, because each tea ceremony may turn out to be the first and the last opportunity and/or encounter within one's finite and unpredictable life time. The phrase, "Ichi-go Ichi-e" ("meeting only once in one's lifetime"), is to succinctly express

what tea ceremony means in Japan during one's life time. Yamamoto explains that "the thoughtfulness of "Ichi-go Ichi-e" ("meeting only once in one's lifetime") among the persons of the tea ceremony contains the depth of the contemplation by the individual persons who are always experiencing between death and life" (Yamamoto, K. Showa 56<sup>th</sup> year (1981): 325). With that in mind, I believe that the Japanese tea ceremony embedded in such rich history of pondering death and life is of great help for both, physician and patient, before and/or after truth-telling executed, to prepare for the worst case scenario of whenever death / dying might be told.

The expression of "Ichi-go Ichi-e" ("meeting only once in one's lifetime") appeared at first in the book written by Yamanoueno Soji, the first apprentice or disciple of Rikyu. It gained recognition as the original thought of the tea ceremony of Japan through the writings of Ii Naosuke (Yamamoto, K. Showa 56<sup>th</sup> year (1981): 326f.).

Ii Naosuke was the chief staff of Tokugawa Shogunate known as "tairo" from 1858 to 1860 almost at the end of the Tokugawa Era or just before the dawn of the Meiji Era. Ii Naosuke put the depth of the tea ceremony in the following context where, after the guest of the tea ceremony left, the host of the tea ceremony who is now alone is to make another tea and then to appreciate the tea quietly on his own, while re-visiting the time spent together, "Ichi-go Ichi-e", "meeting only once in one's entire life", with the face to face exchange of sincere heart between the host of the tea ceremony and the guest of the tea ceremony. With the above description in mind, I strongly believe that Ii Naosuke must have been par excellence as the great master of the tea ceremony of Japan in terms of appreciating the specific tea ceremony itself with dual reasons: the official tea ceremony itself with the guest and the second tea ceremony in solitude.

Speaking of solitude, all of us, particularly the patient at the end of life who will have truth-telling related discussion with his/her physician, are expected to learn the difference between loneliness and solitude, as Japanese tea ceremony is anticipated to give the participants of the tea ceremony the time and/or space to deeply think of the meanings of death and life.

One thing in common among Zeami, Saigyō, and Ii Naosuke is their own thorough contemplation towards the meaning of human life within the limited time given on earth. I strongly believe that "Ichi-go Ichi-e" ("meeting only once in one's lifetime") does not only apply to the persons in the specific context, i.e., the patients at the end of life, but should be considered at all the time, meaning every second of our daily life as well, because every meeting, with anyone

which is seemingly the repetition of the monotonous or routine daily practice, is, strictly speaking, “Ichi-go Ichi-e” (“meeting only once in one’s lifetime”). Thus, we should conscientiously treat each other with respect, while genuinely appreciating the time of “being present with X, any other person, at this moment”, because we can never be at two different places at the same time compared with ubiquitous God.

Japanese philosopher, Nishida Kitaro, said, “I am I, and other human being is the other”. Thus, for Nishida, “I” is focused to completely scrutinize what it really means for the individual to exist in the world. Nishida believes that the deepest philosophy is made by thinking deeply of what the most ordinary daily life really means. Thus, Nishida recommends human beings “to live while thinking” as well as “to think while living” (Ueda, S. 1997: 246f.).

### **3.2 Large spiritual vacuum left among Japanese, because Japan lost in World War II**

Since Japan was defeated in World War II, the religious belief that Japan is the country of god, which was established in the Meiji Era to develop the nationalism of Japan, was certainly diminished. The loss of that ideology left a large spiritual vacuum in the heart of the Japanese people. This spiritual vacuum has not yet been filled and/or replaced by anything. The struggle to fill the spiritual vacuum has been continued to this day.

However, as T. Tanikawa appreciates, the filler cannot be one which cannot be applied to any other people, except for Japanese people. As we are in the era of humanity, the filler must be applied to all humanity (Tanikawa, T. the 33<sup>rd</sup> year of Showa (1958): 7f.).

### **3.3 For here-and-now driven Japanese, thinking of end-of-life is almost impossible!!!**

Today, thinking about death is often avoided in Japan. Japanese people are immersed in life and do not think of abstract concepts of human existence and death, as Tsuchida states, “In reality, thinking of end-of-life is almost impossible to many people, because death is a huge and unpredictable separation which always comes from the other side, without giving us the prior notice” (Tsuchida, T. 2008: 111). These attitudes have created problems in terms of caring for patients at the end of life. On one level, humans seek to banish all thoughts of death and to preserve life at all costs, using medical technology to help them. However, these technologies can then prolong life, while leaving the patient with a very low quality of life. Some related issues are raised by Tsuchida:

However, nowadays, some people have come up to preparing a Living Will and/or Advance Directive for the family and the physician, by thinking of the time when

unconscious situation happens unexpectedly. This attitude shows the change of the individual person's world of consciousness, due primarily to the medical development of life-prolonging or life-saving technologies, meaning to illustrate the increase of societal intervention towards the death of the individual person. Here, it can be said that the disease of our contemporary driven modern civilization has become vividly represented. Or, the wish of existing as a human being can be observed in the patient's situation of being attached to such medical technologies. The entire aspect/sphere of one's existence including death can never be thought of, as we are in the midst of life itself, while adapting ourselves to and depending on the life of civilization (Tsuchida, T. 2008: 111).

Here, an alternative approach is required in which death is accepted as a normal part of life. The role of physicians can then be seen as, in part, about helping people to die well.

### **3.4 Death is a normal part of life with which physicians are expected to help**

Dr. Hirose has written below about all of us who are to die sooner or later, together with the role of physicians.

one thing for sure, 100%, is that we are all going to die. Thus, it is appropriate for any one of us to wish to die in a good way. For physicians, their role is to let people die in a good way. This expression contains no exaggeration of their function, I believe. Because, no one can escape from death, regardless of how much development modern medicine has reached. Likewise, present medicine can never stop human ageing processes, nor can we find complete treatment and/or recovery anticipated to seemingly cure complex diseases (Hirose, T. 2000: 191).

Concerning how patients should be helped to face death, Dr. Hirose offers a number of suggestions, including the importance of the physician's quality, i.e., trustworthiness, while his/her listening to and discussing with the patient. He states:

there are cases in which the help from theologians, philosophers, and psychiatrists should be included to improve patients' psychological stability. However, the most effective way to mitigate the patient's fears against death is considered to let the respected physician invest his own long time to really listen to and then to thoroughly discuss with the patient (Hirose, T. 2000: 124).

Dr. Hirose believes that the responsibility of the physician is to help alleviate all kinds of pain and suffering of the patient, while maintaining the quality of the patient's daily life and considering the serenity of the patient's mind even if the content of death is expected to come.

Physicians should make their best efforts to help to recover patients from their diseases. Even if they can never help them to return to their previous situation without diseases, the duty of physicians is to maintain patients' quality of daily life, to mitigate their pain and suffering as much as possible, to eliminate their fears of death, and to let them peacefully rest physically and mentally (Hirose, T. 2000: 191).

In a nutshell, physicians should change their attitude and behaviour to treat every individual patient as an invaluable creature, rather than as a biological organism, because any medical practice is the venue to act out the patient's rights. Dr. Hirose states:

Physicians should have empathy and compassion towards dying patients as well as respect the requests of patients and their families. Particularly, to show genuine and high respect to dying patients is extremely important. Under modern medicine, the patient has been seemingly handled as one of biology-based living creatures. However, this kind of approach should be changed by physicians themselves who really need to improve their own personality for the sake of respecting the patient's rights (Hirose, T. 2000: 119).

### **3.5 Dying vs. life prolonging machine: Which would be the best for patient autonomy?**

Ever since medical technology emerged to help prolong human life, how to use such technology as treatment has been the huge headache of patients, their families, and medical professionals. I would say that the characteristics of Japan are distilled in the practice of such newly available medical machines.

Whether to use such medical technologies is derived from the following two reasons: (1) the traditional mission of Japanese physicians is to keep the life of the patient as long as possible for which purpose medical machines are used as needed, and (2) the tradition of patient care in Japan requests families to do everything for their loved one in terms of the treatment of the patient at the end of life, otherwise, the family of the patient is exposed to many complaints not only from relatives, but also from other Japanese people in general as against the family tradition of Japan and that the family is to eventually feel ashamed. Fortunately, the hospice and palliative medicine movements are helping to change attitudes towards a more holistic care of patients, as we will now explore.

### **4. Palliative medicine and the hospice movement in Japan for patients at the end of life**

The hospice movement was introduced to Japan from the West in the 1970s. The function of the hospice, however, has not yet been fully understood by the general public of Japan compared with that of the hospital. It is assumed that hospitals help cure patients' diseases followed by resuming their previous work. Thus, it is extremely difficult for ordinary Japanese people to know how terminal cancer patients are treated in hospitals, unless their own family member happens to be a patient in Japan.

Dr. Yamazaki published books on terminal patients which are of great help in understanding what typically occurs in hospitals in Japan, as he states:

In Japan, hospitals are geared towards patients who are treated and cured, and then are expected to return to their work. Thus, terminal cancer patients in hospitals can never be treated as expected being treated. The hospitals of being always busy are not suitable for the terminal cancer patients who require awful lots of time. Thus, the needs of the terminal cancer patients have been neglected in the hospitals (Yamazaki, F. 1996: preface of his book).

Yamazaki M.D. goes on to say why terminal patients can never obtain information on their disease:

Almost all cancer patients of terminal stage are hospitalized without knowing their own cancer's present circumstances. The reason is that the families of the patients and medical staff members take for granted that any information is not given to the patients. Unless the value system embedded in such attitude is changed, I do not believe that the present medical practice of Japan will easily be changed. As long as no change is anticipated, Japanese hospitals will remain as the worst place for any independent persons who want to keep on living in their own ways, right after facts are told (Yamazaki, F. 1996: 248).

Dr. Yamazaki believes that his mission is to help terminal patients continuously live, while understanding their diseases. Regarding the hospice movement, he states:

I want right now to help terminal cancer patients who want to live independently and their families, although the improvement of the hospitals is also expected. I have come to believe that to increase the number of hospices should be the priority (Yamazaki, F. 1996: 249).

Dr. Yamazaki's vivid descriptions of Japanese hospitals not only helped many Japanese people as a "wake up call", but made a bestseller in Japan. The good news so far is that many Japanese hospitals have launched their palliative care wards. However, the courage of Dr. Yamazaki not to accept the lukewarm clinical practice of Japan should never be forgotten as, I believe, it paved the way to improve Japanese patients' treatment and care certainly including truth-telling in Japanese medical practice.

As another Japanese physician, Dr. Hirose has introduced the hospice below.

First of all, the idea of hospice care is to help patients relieve their pain and to maintain their psychological stability, with no treatment which will only make patients experience their pain and suffering. Whether or not hospice care is chosen would be based on the physician's decision of the patient's being unable to live more than six months with present medical treatment. The patient's quality of life is prioritized, even if the remaining time of life might be shortened a little. The second important point of hospice care is to have good communication with the patient and the family, and the third important point is the care of the patient's family (Hirose, T. 2000: 122).



Regarding different expectations of palliative medicine, enlightened Japanese physicians have been scrutinizing the difference in people's expectations between Japan and the West. I know a physician in Tokyo who said, "The Oxford Textbook of Palliative Medicine is the best source to make me fully educated on what is the latest knowledge of palliative care not only in the UK where the hospice movement was started, but also in other parts of the world". This physician has been helping other Japanese physicians in Tokyo about how to use palliative medicine with their patients.

Historically speaking, however, the medical education dominated by paternalism in Japan has been skewed to focus only on the medical aspect of the patient without paying attention to the psychology and value system of the patient. For example, in Japan, the verdicts, so far given to respond to the lawsuits brought up by the families of patients as against the mal-practice of the physicians, have only investigated the physical pain of the patient, whereas the psychological pain of the patient has been totally omitted from the legal concept of pain, although some medical textbooks have been published concerning how to make the classifications of mental disease driven patients.

The reason why no legal consideration is given to the patient's psychological pain and/or suffering is that in Japan there is the strong belief that no one can properly measure objectively the level of psychological pain and/or suffering of the patient, whereas physical pain can be objectively measured. This kind of Japanese judgement on psychology seemingly insults the psychology of the individual human being, which is the engine of every individual's autonomous motivation, prior to taking any action.

I believe that what is urgently needed is to educate ordinary Japanese people on suspicion to begin to end any questions of what hospice and palliative medicine are all about. The philosophy behind palliative care should be taught to Japanese people to change their perception (Miyashita, M. et al. 2008: 376).

In terms of Japanese books about hospice care, the first book was published in 1978 by Dr. Kashiwagi with the title: *Care of People Who are about to Die Shortly*. Thus, let me introduce two key points of this book: (1) the difficulty and importance of telling the truth and (2) the factors of a good listener.

On Dr. Kashiwagi's first key point, the question of whether or not telling the truth would be appropriate is context sensitive. That truth itself is given is to depend on case by case of the individual patient's circumstance. According to Dr. Kashiwagi, if the staff members of the medical

team come up to the conclusion that it is no problem to tell truth, based on their judgement of the patient's and the family's needs, telling the truth would be acceptable and appropriate (1978: 21f.).

The question should be "Is telling the truth truly necessary for the wellbeing of the patient?" The key point is the specific patient's genuine needs to be met by telling the truth. The importance of telling the truth is in what, when, and how the truth is told by whom. Who would be the appropriate person about the appropriate medical issues? This does not mean to succinctly tell medical jargon to the patient who is not yet ready to listen to complex medical terms (Kashiwagi, T. 1978: 23 – 24). On how much information to disclose or truth to tell, it is recommended that no medical jargon be employed by the physician to explain any disease to the patient (Hoshino, K. 1997: 176f.).

I believe that information disclosure and truth-telling are extremely critical issues that depend upon the patient's wish and his/her competence. Knowing or not knowing the truth can both affect, to differing degrees, the patient's anxiety and stability (Shimizu, T. 1997: 124f.). Truth-telling might offer both merit and demerit, depending on how the patient interprets what was told as the truth of the patient's disease. Both bad news and good news should be told, whenever appropriate. We should not completely paint disease with the label of either bad or good news, right after any news is told, because truth is always fragile at any moment of the patient's condition.

On Dr. Kashiwagi's second key point, caring for the dying patient is to psychologically walk at the same pace of the patient's anxiety of death. Medical staff should be ready to keep living with the concern and loneliness of the patient towards death. The following are factors that make medical staff good listeners:

- 1) Staff should respect the feelings of the patient rather than the content of the patient's story to be told, because the patients tend to want the interlocutor to understand what the patients feel.
- 2) Staff should help the patient tell what he/she feels through the staff's asking questions, i.e., "How do you feel?" or "Do you have anything to tell?", because patients are prone to wish to find someone who might be able to listen to their negative feelings.
- 3) Staff should continue the conversation with the patient, without the staff's fleeing from the anxiety of death within the patient's mind. If the patient mentions that he/she believes to have no more days to keep living, the medical staff should say, "Do you think that you are going to become worse?" instead of saying as the response, "You should never say that! You will surely get better!!!" by which the vacuum, emptiness, and hopelessness only remain, right after the staff leaves the patient's room. Thus, medical staff should have the courage to challenge such kind of empty feeling.
- 4) Sitting by the patient's bedside is good for letting the patient (a) know that the medical staff is right now ready to listen to the patient's talk and (b) mitigate psychological distance by having the same eye level between the patient and the staff.
- 5) The privacy of the patient should be considered seriously by the medical staff during any interaction with the patient, because the presence of the family and/or the guest tends to

create a subtle change of the content and/or the flow of the interaction with the patient (Kashiwagi. T. 1978: 43f.).

Following are the typical utterances by Japanese terminal patients. Their frequently used expression of “Moo Shinde shimaitai” (“I want to die”) does not mean these patients are in fact contemplating suicide. In many patients’ cases, it rather means “Shinu hodo kurushii” (“My pain and suffering are so severe, as if I were dead”). The patient whose relationship with the family and/or the staff of the hospital is good seemingly does not think of suicide, according to Kashiwagi’s experiences with patients (Kashiwagi. T. 1978: 48).

This suggestion of Dr. Kashiwagi and his medical staff, based on their real and valuable research with patients at the end of life, does fill in the gap between the anxiety of the patient and the concern of the medical staff. Thus, what is needed for any medical staff, rather than simply jumping to the conclusion of the suicidal tendency of the patient, is to take the time to understand what would be the root cause to make the patient worry endlessly.

Based on the aforementioned communication problems derived mainly from the traditional value systems, Japanese language, and tradition of communication pattern between Japanese interlocutors, Japanese physicians are notoriously bad communicators with patients, except for a few Japanese physicians with good communication skills and an awareness of intra-cultural differences among Japanese patients. Why? In Japan, any clear expression is not preferred as the sign of a shallow or stupid human being. Japanese people are prone to believe that nothing can be said succinctly with a few words only, because everything is doomed to eventually change depending on time, place, and relationship between the interlocutors.

In Japan, a word is weighted with more significance than in the West. One of Japanese sayings is “*Tu yori Iwanai hoo ga mashi*” (“It seems better not to say, rather than saying anything clearly.”). Or, the virtue of being self-deprecating would be the right expression in English to capture the essence of this Japanese characteristic. Strictly speaking, however, who can really understand such Japanese-ness, except for a Japanese person who is highly attentive to the subtle intertwining of linguistic traits, the style of interaction, and more importantly the conscientiousness of the individual creature in Japan? Thus, any Japanese person who happens to be the patient in a foreign country driven medical context needs to figure out when would be the right timing to say anything to the physician of the foreign country’s value system.

As related to palliative care, following is a summary of the crucial problems of Japan on end-of-life treatment:

- Mental pain is not considered as pain from legal viewpoint. Pain in Japan legally means physical pain measured objectively.
- Competency is not a major issue in Japan, because of not succinctly separating the distinction between competent patients and non-competent patients, or sound and non-sound human beings in terms of their decision-making capacity.
- Patients' rights and personal autonomy are still immature notions and not yet developed in Japan compared with the level of Western countries.
- The quality of life at terminal stages has not been fully discussed and not been diffused to the conscientiousness of grassroots people of Japan.
- Many general hospitals are geared towards patients who return to their work right after their operations. Hospitals are not fully prepared for the medical treatment of terminally ill patients.

## **5. Japan Society for Dying with Dignity: Japanese Patient Autonomy duly acted out**

Even under general Japanese driven tendency not to highly value the wishes of patients at the end of life, the Japan Society for Dying with Dignity emerged with living wills to be developed to ascertain patients' autonomy with their decisions to be made on the treatment of end-of-life. In what follows, I will mention this organization's history followed by the interview with the staff in Tokyo in 2010.

The history of the Japan Society for Dying with Dignity is as follows: "Nihon Anrakushi Kyokai" ("the Japan Euthanasia Society") was established in January, 1976. Upon acknowledging the reality of Japan where "anrakushi" ("euthanasia") was widely rejected among Japanese people, in August, 1983, "Nihon Anrakushi Kyokai" changed its name to "Nihon Songenshi Kyokai" ("the Japan Society for Dying with Dignity"). This shift showed the change of emphasis within the association to the idea of "peaceful death" without prolonging life by medical technology, if the patient's disease is incurable or terminal, in comparison with the idea of allowing patients at the end of life to die through euthanasia. Or, "peaceful death" was chosen not only to better reflect the prevailing opinion of Japanese society, but to let ordinary Japanese people understand the new purpose of the association.

When Dr. Ota, the pivotal figure of the association from its start, passed away in December in 1985, about 1,700 members remained, just over half of 3,000 members who had joined at the beginning of the association in the 1970s. After Dr. Ota's death, the association developed "Living Will" movements. (Mitsui, M. 2003: 179 – 180).

The following was part of what was said by the staff of the Japan Society for Dying with Dignity during the interview in 2010 in Tokyo, Japan:

In 1983, our association was renamed as "Nihon Songenshi Kyokai" ("The Japan Society for Dying with Dignity"). The separation from "anrakushi" ("euthanasia") was clearly declared juxtaposed with the views of Japanese people. Under traditional classification, "shokyokuteki anrakushi" ("passive euthanasia") meant "songenshi" ("dying with dignity"). But, what our association advocates is to face death, while maintaining the dignity of human being. For the sake of respecting the wish of the patient to die with the dignity of human being, life-prolonging treatment is withdrawn, not to make the patient die with the intention of killing or shortening the life of the patient. Thus, "anrakushi" and "songenshi" are originally different concepts. If "songenshi" is classified as a part of "anrakushi", the real medical settings of Japan would face confusion, due to the misunderstanding between these concepts.

However, the Japanese physician M. Nishizawa challenges by saying below:

The present association, called "Nihon Songenshi Kyokai" ("the Japan Society for Dying with Dignity"), insists that no similarity exists between the association based "Songenshi" meaning "natural death" in their term and Passive Euthanasia. However, if the natural death claimed by the association is, in reality, to request physicians to withdraw or to stop treatment in terminal stages, and/or to ask for terminal sedation, no difference exists, from medical point of view, between the natural death and Passive Euthanasia (Nishizawa, M. 2005: 20 – 21).

Here, the definition of death is expected through the patient's all things considered, as death is personal business of his/her own socio-cultural factors strongly intertwined as well as the medical aspect of his/her own death. Thus, Dr. Nishizawa's comment, only dragged so-called "the traditional and medical classification of euthanasia", with no consideration of numerous ramifications of death, i.e., psychological, spiritual, social, cultural, and any other aspects of death depending on every individual patient, is to simply vindicate his own skewed standpoint. After discussing with Japanese physicians, I have come to recognize the lack of specialist in Japan who can handle the gap between medicine and law in order to help solve patients' and their families' long buried various problems at the end of life in particular.

### **5.1 Influence of the Japan Society for Dying with Dignity on Japanese society**

In terms of activities, the Japan Society for Dying with Dignity has been: (1) issuing living wills to the members, (2) giving suggestions over the phone to the members, and (3) letting non-members in Japanese society become aware of the importance of living wills.

## Here is current Declaration of the Society on Dying with Dignity

### **JAPAN SOCIETY FOR DYING WITH DIGNITY**

WATANABE BUILDING 201, 2-29-1 HONGO, BUNKYO-KU, TOKYO 113 JAPAN

TELEPHONE: 03-3818-6563    FACSIMILE: 03-3818-6562

#### **Dying With Dignity Declaration**

**( Living Will )**

To my family, my friends, and my medical attendants:

In preparation of a time when I might face an incurable illness and death is near,  
I declare that my wishes are as follows:

This declaration is made by me at a time when I am of sound mind. Therefore,  
this is effective and in full force unless I revoke or withdraw this declaration  
in writing while I am mentally sound.

1. I request that medical technology should not be used to artificially prolong  
my life if modern medicine concludes that my disease is an irreversible or  
incurable one and my life is certified to be terminal.
2. I request, however, that effective pain reduction should be fully achieved  
by any method, such as from the use of narcotics, etc., even though such  
treatment may shorten my life.
3. I request that all life-sustaining procedures be withdrawn if I lie for  
several months in a condition known as a persistent vegetative state.

I express my heartfelt thanks to all those concerned who will faithfully realize  
my requests. I further declare that I hereby absolve these people from any  
civil liability arising from any actions taken in response to and in fulfillment  
of the terms of this declaration.

Signature: \_\_\_\_\_

Date: \_\_\_\_\_

Regarding advance directives, “many Japanese people indicate an interest in undertaking advance directives [in writing, any preferred way of treatment or the power of attorney appointed for any decisions made]” (Miyata, H. et al. 2006. 7:11). Advance directives might be useful “in the Japanese setting when the individual either wishes: 1) to not provide a lot of leeway to surrogates and/or caregivers, and/or 2) to ensure his or her directives in the cases of terminal illness, brain death, and pain treatment, as well as regarding information disclosure” (Akabayashi, A. et al. 2003. 4:5).

However, in the real medical context of Japan, living wills are seldom used. Since ordinary Japanese people tend to reject the notion of living wills, “an advance directive concerning one’s own end-of-life treatment is rarely prepared in Japan” (Miura, H. and Ota, T. 2007: 162). As no legal obligation of what is written in advance directives, “the wishes of competent patients or their advance directives are currently not always given top priority in medical decision-making in Japan” (Asai, A. et al. 1998(a): 1585).

Along with the different viewpoints shown above, the bottom line of how living wills are used would be how much genuinely the conscientiousness of the patient’s wish on treatment and care at the end of life is grasped by the patient’s family members. Here, I can find so-called “litmus test” meaning to examine the degree of mutual understanding between patient and the family concerning how to handle and/or narrow down the differences of viewpoints between the patient and his/her own family members. Right here, medical ethics, i.e., dignity of every patient and patient autonomy, is invisibly and quietly situated, as if it were watching us, human beings, regarding how well and/or how badly each patient at the end of life is treated by the family and the persons related to the patient.

The reality, however, is that the idea of the family is to prevail in Japan, with the Japanese physician’s discretion, on whatever decisions made of the patient’s treatment and care at the end of life. In Japan, I truly wish that medical ethics should be thought of at the middle of sorting out the gap between patient and the family, otherwise, there is a danger that the idiosyncratic reasoning of the family is anticipated to be vindicated for the treatment and care of the patient at the end of life.

## **5.2 The Characteristics of the Japan Society for Dying with Dignity**

In terms of the current configuration of the society’s membership, I received and translated from Japanese into English the following communication of the Japan Society for Dying with Dignity in Tokyo, sent to me on the 11<sup>th</sup> of November in 2010:

As of the 1<sup>st</sup> of November, 2010, the total members registered in Japan were 125,128 persons. In terms of gender, male, 40,618 persons, whereas female, 84,510 persons. The increase of the total number has been about 4,000 persons within the latest 2 or 3 years, as the total number registered was 120,873 persons in April, 2008. In terms of generation, the total numbers aged over 70 years old are 91,887 persons



(73.4%) to show the elderly persons' high percentage within the total registered, in comparison with those of 84,032 persons (69.5%) as of April, 2008. The total numbers aged over 80 years old are 44,052 persons with the increase of 8,000 persons approximately, compared with the figure of April in 2008.

The above summary is to show elderly members increased in the association, together with the increase of about 4,000 persons only as the total, while the increase of about 8,000 persons aged over 80 years old. On the contrary, the decrease of about 3,000 persons has become in reality among the generations of still-working people in Japan or so-called "gen-eki sedai" in Japanese including the persons of the ages in their 60s. Thus, these figures of persons registered seemingly create serious problems for the future of the association.

The content of the above e-mail reveals the characteristics of Japanese people who really hate to think of dying and/or death up until the last moment. Ideally, however, I strongly believe that death and/or dying should be thoroughly pondered at the time when the individual person is sound and healthy physically and psychologically.

The significant features of the Japan Society for Dying with Dignity were mentioned by the staff during the interview of 2010, as I translated into English below:

- Geographically, "Tokai-gata no undo" or "the big city driven movement" would be the appropriate description of our association. The reason is that Tokyo, Kanagawa, and Chiba Prefectures are the major areas of our members.
- Among the registered members of the Japan Society for Dying with Dignity, the ratio between male and female is 1 vs. 2 meaning 32.5% of male vs. 67.5% of female. This ratio between them has been kept for a very long time in our association.
- Although it is really hard to guess the reasons of the women who made their own decision to become the member of our association, if I might, I dare say the following aspects make them join us: (1) the life expectancy would be the one reason, as Japanese women's life expectancy is longer than that of Japanese men, and (2) the women who are experienced in taking care of family members can understand the reality of medical treatment at the end of life and that they themselves become very interested in and highly value the idea of dying with dignity.

According to the staff of the Japan Society for Dying with Dignity, following points are needed resolved in Japan.

- Many problems of medical treatment at the end of life remain unsolved in Japan, i.e., patient autonomy, lawsuits of treatment executed, and media coverage of withholding and/or withdrawing treatment. The interest of Japanese people in treatment at the end of

life has increased, due to many tragedies happened including at the Tokai University Hospital, on the lawsuit of the Jehovah's Witness who refused blood transfusion, which ended with the verdict of the Supreme Court of Japan in 2000 to respect the patient's decision, at the Kawasaki Kyodo Hospital in 2002, at the Imizu City Hospital ("Imizu Shimin Byoin") in 2006, and many other cases reported.

- What should be learned from patients' tragedies is to ponder where to draw the line at the intersection of medicine, law, and ethics, especially how to apply "dying with dignity" for the patient's withholding and/or withdrawing life prolonging treatment. Some guidelines are out, without their being digested enough by Japanese people. In terms of patient autonomy, Japan has no specific law tailored for patients' making decision on treatment among options, except for the Article 13 of the Constitution of Japan to be referred to. Thus, "patient autonomy of making decision on treatment" is "unwritten rights" in Japan.
- In terms of research, there has been no research carried out in the real medical settings of Japan on the end-of-life medical treatment of patients. Under such reality, the investigations into end-of-life medical treatment conducted by the Yomiuri Newspaper in 2006 and 2008 are the most significant in revealing the reality of what happens in Japan (to be discussed in Chapter 4).

### **Conclusion to Chapter Three**

In this chapter, I have demonstrated the pervasiveness of social convention and traditional values in shaping Japanese society and medical practice. These features of Japanese life continue to influence patient care. Whereas patient-centered medical care has come to be emphasised in the West, medical paternalism remains widespread in Japan. The paternalism based medical education of Japan has not been forgotten in history, but is still vividly living within many Japanese physicians as the solid vehicle of thinking and acting out their daily attitudes and behaviours, i.e., whenever talking to their patients. As Miura and Ota state, "No system exists for how to make decisions of end-of-life treatment. Thus... there is the danger of the doctor's decision becoming the monopoly" (Miura, H. and Ota, T. 2007: 163 – 164). An additional difficulty is the problem of disagreement among family members about end-of-life care and whether or not to prolong treatment: "The dilemma in real medical settings is that there is no final decision made on end-of-life treatment, due to no consensus of family members" (Miura, H. and Ota, T. 2007: 163). Here the patient's wishes are not taken into consideration and/or not acted out, while the family is figuring out what any consensus would be. What is desperately needed right now is a method or strategy to make patient-centered treatment become reality: "The system to actualize patient centered end-of-life treatment must be created" (Miura, H. and Ota, T. 2007: 164).

So far, the emphasis has been put on the preservation of life at all costs, irrespective of the wishes of the patients. As Dr. Igata, Chairman of the Japan Society for Dying with Dignity, stated,

“we, physicians, were educated to do our best to prolong life up until the last moment” (Igata, A. 2004: Opening speech). Thus, Dr. Igata stated, “I admit with my great regret that I kept giving so many terminally ill patients pain and suffering in the past. Thus, physicians should put themselves into the patient’s situation, and should share the patient’s pain and suffering, and then should obey the patient’s own wish” (Igata, A. 2006: 1533). Dr. Igata’s statements above are great confessions on the lack of interaction between the patient and the physician. Dr. Igata ventured to succinctly express the conventional problems of Japanese physicians’ education. I hope any other Japanese physician will initiate re-thinking or stopping the tradition of Japanese medical education with paternalistic practices, as Dr. Igata facilitated in his very candid way backed up by his experiences with many Japanese patients.

Gianni Vattimo, an Italian, from Turin University, and one of our contemporary world famous philosophers, gave the Gifford lectures at the University of Glasgow in June 2010. One of his statements is “Being is an event for human beings to actively participate as an interpreter of the event”. If we can take such attitude as Gianni Vattimo towards “being” as human being, I believe that any one of us would be able to change the attitude of so-called “monotonous or routine daily life” to the excitement of every moment as only once experienced in the individual’s entire lifetime. Thus, each moment of being in the human world would surely become treated as precious time.

As one example of actively participating in the event of being human, Mr. Terry Pratchett, a famous author from the United Kingdom, has started to claim himself as Mr. Alzheimer, because he is a patient of Alzheimer’s disease. What he really wants is to suggest the people of the United Kingdom change their mindset to cope with death. I believe his suggestion is the great step forward to (1) letting all walks of life in the UK become aware of what death is all about and (2) helping to diffuse the discussion of death as acceptable, as a part of their daily life. I wish someone in Japan were encouraged to begin a similar movement as soon as possible.

In the next chapter I examine in greater detail the concrete ramifications of Japanese cultural norms and traditions on truth-telling and patient care at the end of life, drawing on various research, studies and surveys.

## **Chapter Four**

### **Research into truth-telling and treatment practices in end of life care in Japan**

#### **Abstract to Chapter Four**

In Chapter 3, the traditional values of Japan and their present day ramifications are pointed out as the vehicle of understanding what kind of Japanese socio-cultural facets and human relationships have been clearly fabricated to create the medical climate of Japan including its history and clinical practice in which medical ethics is embedded. Chapter Four of the thesis builds upon chapter three by further explaining what has been happening in Japan up until the present day in terms of medical decision-making and truth-telling of diagnosis, treatment, and prognosis of disease regarding the patient at the end of life. The contour of truth-telling practices of Japan will be shown to be heavily dependent upon the cultural traditions and etiquette of Japan, which tend to make the Japanese patient subject to the wishes and influence of the physician and family members. As we shall see, whether or not to tell truth to patients largely remains the decision of Japanese doctors. Physicians' clinical practices either promote truth-telling or more frequently accept the present status quo of assuming that patients do not wish the truth to be told to them, thereby maintaining the Japanese tradition of paternalism.

In this chapter, the focus will be on investigating research studies and media surveys of how truth-telling of disease has been executed from Japanese physicians to Japanese patients and their next of kin (who are usually family members) at the end of life and on the practices and procedures of medical decision-making at the end of life – especially concerning the withholding and withdrawal of life sustaining treatment. I examine qualitative research as well as quantitative research into these practices, as published in major journals and books both in Japanese and in English.

This chapter begins with explaining the results of the latest surveys on truth-telling and attitudes to the end-of-life treatment and care in Japan. Then, by following the template used in Chapter 1 and Chapter 2, I will discuss how medical practices of truth-telling on diagnosis, treatment, and prognosis of disease have been executed in Japan. The examples of good practices by enlightened Japanese physicians on how truth is told to patients are presented followed by four notorious lawsuits of pseudo euthanasia 'accidents' and truth-telling driven mal-practices in Japan. The remaining section of this chapter deals with the ramifications of truth-telling in Japan, i.e., Japanese guidelines of patients' treatment at the end of life and current treatment and care oriented issues with research addressed mostly to patients at the end of life on how well they are treated by medical staff as well as how well the patients are cared for by their families.

## 1. Research, studies, and surveys on truth-telling and treatment at the end of life in Japan

Regarding end-of-life interwoven problems, the following chart provides the main results of the investigation conducted by the Ministry of Health, Labour and Welfare of Japan in March 2008, based on the Ministry of Health, Labour and Welfare of Japan. 2008. *The Investigation of End-of-Life Medical Treatment*. March, 2008. This large-scale survey provides valuable evidence of the attitudes of a wide cross-section of Japanese society to issues concerning end of life care.

### Total Persons targeted as the subject and the Feedback Ratio

	Total Persons targeted	Total Feedback received	Rate of Feedback received (%)
Japanese people in general	5,000	2,527	50.5%
----- (Among the above, persons aged more than 70 years old)	---	(457)	---
Medical Doctors	3,201	1,121	35.0%
Nurses	4,201	1,817	43.3%
Care Staff	2,000	1,155	57.8%
Total	14,402	6,620	46.0%

Note: This survey was made by sending questionnaires to the persons chosen randomly.

### Question 1. On Interest in End-of-Life Medical Treatment

Answer: The majority of Japanese people are interested in end-of-life medical treatment. The interest of medical professionals is higher than that of people in general. Among people more than 70 years old, 72% were interested in end-of-life medical treatment compared with 79.5% of Japanese of all ages.

### Question 2. Whether or not diagnosis, treatment, and prognosis wanted to know

Answer: The majority of Japanese people wanted to know their own illness based diagnosis, treatment, and prognosis, just the same as the previous survey of 2003. Among the people of more than 70 years old, 65% wanted to know compared with 77% of Japanese of all ages.

### Question 3. Living Will

Among respondents more than 70 years old, 42.5% agree with the concept of a living will compared with 61.9% of the respondents of all ages. Among those who agree to a living will, there are two further details: the persons who would request that living wills should be legalized are 34%

of Japanese of all ages (54% of medical staff members), and the persons who would not request that living wills be legalized are 62% of Japanese of all ages (44% of medical staff members). Among people more than 70 years old who agree with the idea of the living will, the numbers to request living will be legalized are 29% vs. 34% of Japanese of all ages mentioned above.

### **The 10-year-comparison between 1998 and 2008 on Living Wills**

Year	<b>Agree with <u>Living Wills (%)</u></b>		<b>% who believe Living Wills are unnecessary</b>		<b>Disagree with <u>Living Wills (%)</u></b>	
	Medical doctors	Japanese of all ages	Medical doctors	Japanese of all ages	Medical doctors	Japanese of all ages
1998	69.5%	47.6%	17.8%	34.8%	4.1%	2.9%
2008	79.9%	61.9%	13.1%	21.8%	1.8%	2.4%

The above chart shows that the concept of living will has become more known and widely accepted by an increase of more than 10% in the ten years between 1998 and 2008 for both Japanese medical doctors and Japanese people of all ages.

### **Question 4 – 1. Decision-making concerning End-of-Life Medical Treatment**

There is the gap of 40% between Japanese people in general and Japanese medical doctors in terms of how much the content of living wills would be respected. About 40% of Japanese people in general believe that living wills should be respected by medical doctors, whereas more than 80% of medical doctors say that they would respect living wills.

If no confirmation of the patient's wish is made, using the wishes of the patient's family and/or the person most closely related to the patient for making decisions is accepted by 58% of Japanese people in general, whereas by 72% of medical doctors.

### **Question 4 – 2. On the Execution of End-of-Life driven Treatment**

If the prognosis of the terminally ill patient becomes certain only to live for less than 6 months, no life prolonging treatment is wanted by 72% of the people of more than 70 years old vs. 71% of Japanese of all ages. This survey in 2008 seems to reveal a consensus among Japanese people not wanting life prolonging treatment, if they have the prognosis of less than 6 months to live.

If brain damage and loss of consciousness happen, the wish for no life prolonging treatment becomes higher than that of the terminally ill.

On the type of treatment course for those with less than 6 months to live, Japanese people want palliative care and to die naturally.

### **Question 5. Hospital or home-based care at the end of life**

If terminal disease with less than 6 months to live becomes real, 63% of Japanese people would want home care, whereas 80% want palliative care in hospital, when dying is to come shortly. 66% of Japanese people think that they could not be adequately taken care of at home up until the last moment, because of (1) the burden on the family who takes care of the patient at home; (2) worries about the response to any sudden change of the condition of the patient; (3) the concern over whether the patient could quickly be accepted by hospital, if the patient's condition changes; (4) the financial burden seems to become very large; (5) no medical doctor would probably come to see patients at home; and (6) no national care system is available enough to cover patients at home. Home-based care will be further discussed in detail later in this chapter.

#### **1.1 Research, studies, and surveys of truth-telling to cancer patients**

In the medical literature, much of the research into the matters of truth-telling and end of life care in Japan is based on studies of cancer patients. Thus, this section is geared towards discussing cancer diagnosis and cancer patients at the end of life. Compared with the past, right now in 2014, the Japanese medical climate has been shifting in its approach to cancer. This is because (a) many different and positive attitudes to fight against cancer have been taken by Japanese cancer patients and (b) there is a new focus on education concerning “daily-life-driven-diseases” including cancer. This lets ordinary Japanese people become aware of the importance of adopting healthy habits in daily life, i.e., cutting down or stopping heavy smoking, avoiding excessive alcohol consumption, eating healthy foods, and avoiding any other unhealthy habits, in order not to trigger cancer and other contemporary diseases. However, Japanese people are often fearful of the word, “cancer”. As Dr. Hirose has said, “cancer implies death to ordinary Japanese people” (Hirose, T. 2000: 174). Generally speaking, cancer was for a very long time considered equal to a death sentence. This still shapes the beliefs and fears of Japanese people, and affects the motives of physicians in their decisions about whether or not to reveal cancer diagnosis to patients. Consequently, “the physician faces the dilemma between (a) telling facts to the patient and respecting his personality and (b) not telling facts, i.e., cancer, to avoid mental damage from the patient” (Niimi, I. 1984: 97). This tension is evidenced in the various research studies that have been conducted into truth-telling to cancer patients, as will be seen below.

## 1.2 Whether physicians divulge truth of diagnoses to their patients

Regarding cancer to be told or not, in 1985, Dr. Mouri, one of the veteran medical doctors in Japan, stated “throughout my 50 years as an internal physician, I have not said directly to any patient that ‘Your disease is cancer’, although I myself want to be told” (Mouri, K. 1985: 141 – 142). Dr. Mouri goes on to say how difficult it is to tell facts directly to patients who are terribly worried about their disease which deteriorates daily. By focusing on the specific patient who happened to be his former teacher to whom he feels extremely indebted, Dr. Mouri repeatedly confesses how hard it is to pretend all is well and/or simply to tell a lie about the patient’s disease, whenever he is asked by the persons related to the patient. Dr. Mouri, however, states that if he were a patient, he would want his diseases to be told to him by the physician, since he would prefer to avoid any awkward relationship between himself as the patient and the physician taking care of him. His candid reflections not only reveal the conflicted issues of truth-telling at the end of life, they also highlight the importance in Japan of maintaining good professional relationships and indirectly disclose what the typical Japanese medical doctors’ daily practices were in the 50 years, before 1985.

As Dr Mouri’s case highlights, Japanese people have been struggling with the question of whether cancer patients should be told of their diagnosis of cancer for decades. In 1989 when the Ministry of Health and Welfare of Japan asked 329 physicians whether they tell cancer diagnosis to terminally ill patients, 55.5% said they never tell, 17.5% said they seldom tell, and 13.3% said they sometimes tell. However, all the respondents reported that the patients’ families were told of the patient’s cancer diagnosis based on Hiraga, K. (ed.) 1989. *Annual Report of the Cancer Research* (1-30). pp. 117 – 124. In 2005, the Ministry of Health, Labour and Welfare of Japan reported that 46% of terminal cancer patients knew their diagnosis based on the Ministry of Health, Labour and Welfare of Japan in 2005 concerning *Death with dignity questionnaire research*.

There is a huge gap between (a) the desire of an individual to know about the individual’s own cancer and (b) the practice of telling diagnosis of cancer to cancer patients in general. The ratio of the individuals who subjectively wished to know about their own cancer was almost two times higher than the doctors of the same individuals who wanted to let cancer patients know about their cancer. Thus, Tanida in 1994 reports that only 13% of doctors tell diagnosis of cancer to their patients, due to the prevailing Japanese paternalism, and not enough information of cancer is obtained by the general public of Japan (Tanida, N. 1994: 50).

In terms of whether a diagnosis of cancer is directly told to patients, Japanese physicians have tended to exercise their discretion. For instance, in a survey of physicians published in 1991, only



3% of the respondents directly told their patients about their cancer diagnosis. The majority of respondents came to a decision about whether to tell patients the truth about their diagnosis “depending on the circumstances” (Takeo, K. et al. 1991: 45). Likewise, in a study of seven Japanese physicians who participated in a two-hour group interview, Dr. Asai pointed out that “Different physicians had different approaches to the disclosure of a diagnosis of cancer and to informed consent” (Asai, A. et al. 1997: 324).

Here I need to ask the reason “WHY?” Because particularly in Japan, both: (1) truth-telling and (2) patient-physician relationship can never be separated out. Japanese doctors are prone to offset between (1) how much relationship is created with the patient and (2) how much truth-telling is executed to the patient. Thus, it appears obvious, irrespective of telling cancer to patient as diagnosis or not, that Japanese physicians are prone not to tell truth of diagnosis to Japanese patients, as pointed out that Japanese psychiatrists give, at around two times higher a degree, only a vague diagnosis on schizophrenia in comparison with those communicating with patients of North America (McDonald-Scott, P. et al. 1992: 147 – 157).

In at least one Japanese teaching hospital, the majority of terminal cancer patients treated with morphine were not informed of the real names of their diseases, and they were seldom involved in any DNR (do not resuscitate) decision. Thus, this teaching hospital practice reveals the urgent need for ethical education “to improve decision making process in the end-of-life care” (Tokuda, Y. et al. 2004: 264). I believe that how to apply medical ethics to patients can be learned only from the doctor’s interaction with the patient. Dr. Ooi believes that mutual understanding has not yet been developed between patients and physicians. He remarked, “the biggest problem of Japan is that no real exchange of thought is made between the physician and the patient on end-of-life issues. Thus, even in the present Japan, no patient has a right to solely decide life and death matters” (Ooi, G. 1989: 190 – 191).

Long and Long have remarked, “Japanese physicians ardently feel that by revealing the diagnosis to a terminally ill patient, they will extinguish the patient’s hope. If the patient has no hope, he will not ‘fight to live’ and in many cases may even commit suicide” (Long, S. and Long, B. 1982: 2103). The risk of suicide is still a key reason for not telling the truth to patients, as stated below.

In the name of doing good, the diagnosis and prognosis usually are withheld from the patient. When informally asked why this should be the case, Japanese health professionals often give three reasons: if patients are told this bad news, they will

stop fighting, give up, and die or become depressed or commit suicide” (Davis, A. and Konishi, E. 2000: 90).

The benefit of not telling truth of the patient’s disease is also reported in the literature. In Maeda’s survey, the uninformed terminal liver cancer patients had “a peaceful last stage before death” (Maeda, Y. et al. 2006: 5:6).

Dr. Nishikawa observes that there are practical difficulties associated with truth-telling. These include errors of diagnosis, because errors of the patient’s disease can occur, regardless of the medical education and clinical experience of the individual physician. Thus, Dr. Nishikawa states:

There are six physicians in the Department of Psychiatry where I have been working. Thus, many differences exist among us in terms of which medical school we graduated from, what kind of medical education was taken, how long we have worked as physicians, and different point of views appeared ... However, the diagnosis and the treatment of the patient sometimes do need an urgent decision. There are cases in which full responsibilities cannot be given to any physician of a relatively short clinical experience. Errors of disease diagnosis can happen, as far as any physician is as a human being, regardless of any physician with sufficient experiences (Nishikawa, K. 1982: 25).

I believe that the above statement is extremely valuable and educational for any Japanese persons, Japanese medical doctors in particular, because of his candid confession of medical errors to be succinctly revealed backed up by his experience as physician. However, this does not justify keeping the truth of diagnosis from patients.

### **1.3 The influence of the Japanese family on truth-telling in the medical setting**

A double standard of Japanese people tends to operate concerning knowing about the diagnosis of terminal disease. Generally speaking, those asked express a desire to be told about cancer in their own case but, in the case of others (even if the other is a member of that person’s family), he/she would prefer not to tell the other about the cancer. This tendency is highlighted by Mitsuya, as quoted below:

There is a double standard in truth-telling in Japan: in a newspaper survey in 1981 – 1985, 53 – 56% of respondents expressed their desire to be informed of their own cancer diagnosis, while only 10 – 12% of respondents preferred to inform the patient of the diagnosis if one of their family members has cancer (Mitsuya, H. 1997: 279).

According to the study of B. Gabbay, when asked to whom a cancer diagnosis should be told, 229 (94%) of the Japanese residents indicated “both --- the patient and the family” compared with the U.S. residents, 54 (53%) of whom indicated the “patient” only (Gabbay, B. et al. 2005: 618).

Regarding the disclosure of a poor prognosis, 175 (72%) of the Japanese residents again preferred to disclose the prognosis to “both --- the patient and the family” compared with 46 (45%) of the U.S. residents, who preferred to disclose to the “patient” only (Gabbay, B. et al. 2005: 618).

Based on K. Hirai’s research, the ratio of telling diagnosis to both parties of the patient and the family of the patient from the physician was 30% by revealing the present status quo of Japan that telling diagnosis has not yet fully been executed. However, the family of the patient whose loved one’s diagnosis was directly told to the patient from the physician has shown an affirmative evaluation towards such action taken (Hirai, K. et al. 2006: 184).

Japanese doctors often concern themselves and make decisions on the basis of the assumed wishes of patients’ families, rather than the actual wishes of patients. For example, artificial nutrition and hydration are considered as “a life-prolonging measure in the hope of meeting the expectations of families who, the physicians believed, wanted to keep the patients alive” (Aita, K. et al. 2007: 7: 22). This statement shows the typical Japanese physicians’ assumption that the family of the patient would want to prolong the patient’s life. In here, I wonder if the tradition of Japanese medical education to preserve the life of the patient as long as possible would vividly be living in the physicians’ mindset as juxtaposed with giving “hope” to the patient and the family. Anyway, this mis-communication, not directly asking what the patient and the family really want, demonstrates Japanese doctors’ arrogance and discretion under the hierarchical doctor-patient relationship even in the 21<sup>st</sup> century.

Mr. Hosaka, non-fiction writer and critic, wrote about informed consent newly imported from the USA in comparison with the Japanese tradition of telling the name of the patient’s illness with the initiative of the physician to agree with the patient (the family of the patient often meant in Japan), along with the example of “the agreement of the operation”, the form to be exchanged, before the operation, between the physician and the patient [so many cases the family of the patient], does state “No complaints will be made” in order to meet the physician’s preference (Hosaka, M. 1993: 22 – 23).

In the tradition of Japan, patients do not officially complain on the content of the Japanese consent form exchanged between the family of the patient (rather than the patient) and the physician before any operation. This means that family perspectives frequently dominate the wishes of patients. Thus, organ transplants are rarely made, if the family of an incapacitated brain-dead patient says “NO!” to donating organs from the patient. This occurs irrespective of the wishes of the patient. Here the question would be: What is the responsibility of the family, if the different viewpoint of the patient is not actualized with respect?

Disagreements easily come up with treatment options of an Alzheimer's case, when no statement of the patient's intentions is available. Thus, the conflicts of how to make decisions of the patient's treatment would appear between the physician's opinions and the family's viewpoints. Despite the high regard paid for the consensus created as the decision of persons involved, in reality consensus-making is the most difficult task to achieve in Japan. What is more frequently at play is power struggles within the family of the patient on the patient's treatment at the end of life, such as where the patient should be cared for (either at hospital or at home), who is responsible for the patient's daily health care, and who is to deal with the patient's psychological, socio-spiritual, and any other problems.

Further investigations are needed for the intricate business between the patient and the family of the patient in Japan to discover how the following pivotal problems are idiosyncratically intertwined: the "mature" / rational patient's hope at the end of life vs. the traditional family's wish, the dying patient's autonomy vs. the "mature" family's responsibility for the patient at the end of life, and the patient's wish of how to be remembered as a human being vs. the family's wish of how to remember the loved one, once she/he has gone.

While these trends in family control are visible in Japan, I would suggest that it depends on individual families how much the family of the patient controls truth-telling, i.e., the patient's autonomy may be fully respected by the family, the patient may need the family's suggestion, or the patient may fear the family's entire control, and any other combination of the power balance between the patient and the family of the patient. The pivotal question is: How are the patient and the patient's family connected on truth-telling practice? Having the family mediate the news may be the individual patient's choice and/or the actualization of the patient's autonomy through informed consent: "if a patient who holds an interdependent view has a propensity to prefer a family-facilitated approach, providing this approach to informed consent may indeed be respecting patient autonomy" (Akabayashi, A. and Slingsby, B. 2006: 13).

However, Tamura argues "it is dangerous to apply a family-facilitated approach on the premise that the family is a single cohesive unit. A family consists of multiple members who have different thoughts and feelings, with complicated and intertwined relationships between family members" (Tamura, C. 2006: 16 – 18). It is in this reality that disagreements frequently go on the surface.

One of the major physicians who contributed to the introduction and implementation of palliative care medicine to Japan stated, "In the case of elderly patients, it is not common to ask about their own diseases directly to the physician ... Thus, no telling truth is made voluntarily

from the physician ... 'The families of the elderly patients are prone to be thinking twice on telling the name of diseases to the elderly patient' (Kashiwagi, T. 2004: 50 (316)f.). I suspect such a voluntary retreat of physicians from telling truth has been exercised since the beginning of palliative medicine in Japan. If physicians have not been asked about their condition directly by elderly patients, then remaining silent and not telling the truth is considered the best policy. Under the medical tradition of Japan, dominated by paternalism, patients cannot obtain the full truth of their condition if the families of the patients ask the physicians not to tell the truth to their loved one, the patient.

According to Ruth Macklin, however, there are more complex relational dynamics at work among doctors, patients, and the families of patients. This gives rise to complicity on the part of the patient in the secrecy and withholding of medical information:

Patients [in Japan] want to have an “edited” version of the truth. They enter a tacit conspiracy with their family and the physician to avoid a difficult subject. This results in the family taking over all responsibility and decisions for the patient’s illness. Although many patients will guess and come to know the truth eventually, they still will not ask directly. This behavior is rooted in the Japanese ethos in which silent endurance is a virtue. The aim is to make dying easier, not to invoke a dogma of telling patients the truth. Patients want to die as calmly and as peacefully as possible, and that goal is more readily achieved if they remain ignorant of their prognosis (Macklin, R. 1999: 104).

I would argue that Macklin’s perspective carries some validity, but is not the whole story. The characteristics of Japanese patients are very varied. Any particular Japanese patient differs from another Japanese patient depending on what level of education he or she has earned, what sort of work has been experienced so far, where he or she lives (i.e., in a big city like Tokyo or a small town), what kind of parents raised the patient, what kind of social and/or religious ideas he or she has, what norms he or she has on how to use one’s assets/money on the specific short and long term goals throughout life, the differences of physical, psychological, social, and spiritual pain and/or suffering of the patient, and any other aspects needed to understand the individual Japanese patient as a whole.

Thanks to the increase of life expectancy in Japan, the illusion of death hardly to come has been accelerated juxtaposed with the tendency of ordinary Japanese people not to want to think of and/or talk about death. In general, the patients currently facing end-of-life were born before World War II when Japan was under the strong vertical traditions of hierarchically structured society. Thus, they tend to behave in a reserved manner or simply obey physicians without asking

anything. However, the exceptions to this norm exist even among Japanese people born in the Meiji Era who wish to discover the truth of their diseases by asking questions to the physicians to actualize who he or she is as a patient as well as a human being.

Regarding how physicians communicate bad news with patients, Dr. Hoshino states “the Japanese physician tries to avoid disclosing any distressful news directly to the patient, especially without couching the information in allusions or some other indirect method. More likely, the physician will first meet with the family. But even in these discussions, the references to the truth of the patient’s condition will be oblique” (Hoshino, K. 1995: 74). Additionally, Dr. Hoshino pointed out the difference between the East, Japan, and the West, the USA, by quoting the following very well-known sayings: “the nail that sticks out gets pounded down” as the norm of Japan vs. “a squeaky wheel gets the grease” as that of the USA. (Hoshino, K. 1995: 72). That is to say, Japanese society values conformity and social etiquette, and frowns on those who defy social convention, disturb the status quo or act in an individualistic manner. By contrast, American society valorizes individualism and notices and rewards those who speak out against the system.

#### **1.4 Telling truth of Prognosis to patients and their families**

When prognoses are told to advanced cancer patients, Japanese physicians tend to give optimistic views to patients, whereas they tell more pessimistic prognoses to the families of the patients. The reason behind this inconsistency among Japanese physicians is that the power of the family cannot be overlooked. “Family consent” is definitely needed, prior to giving the patient a serious prognosis (Akabayashi, A. et al. 1999: 1263).

In terms of accuracy of prognosis, Dr. Hinohara, one of the most famous Japanese physicians, stated, based on his long experience, that “I think that information of prognosis of the patient must be the art of medicine rather than the science of medicine, although the diagnosis of the patient can be made scientifically” (Hinohara, S. 2007: 95). Along with this suggestion to other Japanese physicians to think carefully before discussing prognoses with patients, I could imagine that Dr. Hinohara would have meant any grave influence to be generated on the psychology of the patients and the families of the patients, once any prognosis has been told to them by the physicians.

Despite the difficulties involved in how to tell prognosis, the following instances are to verify how important it is to tell even something of the prognoses to the patients who have not yet recognized the reality and/or gravity of no recovery ever being anticipated. One nurse, at Kumamoto University Hospital in Kumamoto Prefecture, Kyushu, was asked strongly by the

patient who said angrily, “What on earth has my physical body been so far?” Thus, the nurse advised the family of the patient to tell the truth that there was only a short time left, without revealing cancer. As the result, the patient could recover psychologically and said, “I understand what was told to me. I appreciate your help so far given to me. I wish to die, as if I were to be sleeping.” In this case, the nurse’s judgement of the patient’s capacity to accept the truth (not to tell cancer, but to indirectly tell other related issues) was the key to helping the patient make decisions on how to use the time left, while having a memorable time with the family by revisiting the life passed. Telling the truth requires finding the appropriate way for the sake of meeting the patient’s feelings and the timing of what the patient wants to know (Muto, K. 2003: “Ippan endai” (23) – 4). Here, I can see how essential it is to read the patient’s genuine feelings and to follow them with the appropriate action of medical staff to let the patient spend comfortable days at the end of his/her own life.

More time should be spent by medical staff on the following two stages: (1) medical aspects, i.e., what is the diagnosis of the patient’s disease, what is the treatment of the patient’s disease including options and/or alternatives, and what is the prognosis of the patient’s disease and (2) interaction driven aspects between the physician and the patient, i.e., how to tell the truth of diagnosis, treatment, and prognosis to the patient in order to make sure the capacity and readiness of the patient to accept bad news.

Particularly, how to disclose prognosis should be thoroughly thought out in order to make the patient digest any unfamiliar medical words as easily as possible to eventually gain a stable condition psychologically. What makes the patient whose prognosis has been told change to have peace in his/her mind is the utterance of the nurse to be certainly living with the patient up until the end of the patient’s life, enabling the patient to face death with less difficulty. The role of the nurse is genuinely to respond to and/or to support what the patient truly wants to receive from medical care (Shibusawa, H. et al. 2008: 247).

The worst case scenario of any bad prognosis to be told is directly related to the death of the patient. Dr. Nishikawa very candidly expresses that his perception of death has become numb through observing many deaths of his patients simply as a physician in comparison with his own death.

As a physician, I have been confronted with many deaths. However, I have recognized that the consciousness of death has become numb in my mind, as opposed to my experiences of the patients’ deaths. The death, in all occasions, was not related to my own death. The person who suffered was the patient, and the person who was going to die was the patient (Nishikawa, K. 1982: 31).

Based on his own cancer directly told, Dr. Nishikawa acknowledged how loneliness and powerlessness are profoundly experienced by patients:

I strongly believe that I am merely a patient, too. The status of the patient is weak. Whenever the patient disagrees with the physician, the patient has to recognize the situation of being thrown out by the physician. It is difficult for the patient to live alone in the midst of the pain, suffering, anxiety, and/or fear of the disease. The patient has no choice, but to obey the physician up until the last moment. The more the disease gets serious, the more difficult for the patient to be consulted by any other physician, against the decision made by the physician (Nishikawa, K. 1982: 182).

Although death is surely everyone's final business, how to tackle death would vary among the individual persons, physicians included, even within the limitation of medical tradition, i.e., paternalism of Japan, which forces the patient to limit his/her own wish of obtaining any second opinions in particular. It has been more than 30 years, since Dr. Nishikawa's very valuable and succinct descriptions were published in Japan. Today, some leading Japanese hospitals have added on their websites the notice: Second opinions to be discussed, as a brand new trend.

### **1.5 The case of Dr. Yamazaki's patient**

In 1996, Fumio Yamazaki M.D. published his book called *Byoin de Shinuto iukoto. (Meaning to die in Hospital: For patients, nurses, doctors and all other people)*. Its discussion of end of life care in Japan made it a best-seller. In this book, Dr Yamazaki relates the case of one of his patients, who was suffering from stomach cancer. The case captures some of the typical approaches to truth-telling of diagnosis, treatment, and prognosis about cancer that are seen in Japan, and illustrates the ingrained paternalism within families and within the medical establishment. Such attitudes are commonplace in Japan, and taken for granted in present-day Japanese society. By translating the relevant parts of this book into English, and by discussing this case, I hope to bring to light how terminal patients should be treated in medical settings – not only in Japan but throughout the globe. This patient's case involves: (1) the concept and practice of truth-telling; (2) the patient-family relationship; and (3) the physician-patient relationship. As we will see, this patient's case demonstrates the way that family members and physicians – who are highly motivated by concern for patients – can, nonetheless, prevent the patient accessing the facts about his medical condition and confronting the truth about his disease. This type of Japanese paternalism undermines patient autonomy and denies patients the opportunity to come to terms with their terminal condition.

Eighteen months earlier, Dr. Yamazaki saw a patient who very politely explained his disease based symptoms and conditions. After conducting various tests, Dr. Yamazaki concluded that the patient



had stomach cancer. Dr. Yamazaki said to him, “Some cancer cells were found, therefore, the best treatment is to do operation” (Yamazaki, F. 1996: 215). The patient became nervous and asked, “Do you mean stomach cancer?” (Yamazaki, F. 1996: 215). The physician replied, “I think you had better consider yourself with stomach cancer, due to some cancer cells certainly found” (Yamazaki, F. 1996: 215). The patient asked, “Is the operation the only treatment? Would I be cured?” (Yamazaki, F. 1996: 215). Dr.. Yamazaki said,

Since all treatments are not always effective, I can never say that you will be cured. We, physicians, however, begin to treat patients with the intention of helping patients to be cured. Thus, the operation must be the first step of the intention. I believe that a long treatment is just about to begin including the operation. As a terribly difficult time might come once in a while, I do not want to tell any lie. Let’s work together, shall we? (Yamazaki, F. 1996: 216).

His patient replied “I understand completely what you told me. I sincerely ask you to treat my disease” (Yamazaki, F. 1996: 216).

His operation was executed one week after his hospitalization. However, the cancer within his stomach could not be taken out, because the cancer had been intertwined with the artery of the liver, although, fortunately, two thirds of his stomach were normal. The operation to remove the cancer was therefore unsuccessful. The patient had high hopes following from the operation. As a result, unlike at the earlier meeting between the physician and the patient, Dr Yamazaki and the other physicians who were in charge of this patient could not tell the patient the truth about the operation. Rather than explaining to the patient that it was impossible to remove the cancer, the physicians, including Dr. Yamazaki, instead ‘protected’ the patient from the bad news. (Yamazaki, F. 1996: 216).

Here, I will make some observations about Japanese medical practice. This sort of paternalism is a common feature of Japanese medical practice. Generally speaking, the expectations of Japanese patients facing an operation are extremely high. Most are unable to imagine the operation could turn out to be unsuccessful, such is the high regard and respect for their physicians. Not telling the truth of unexpected or bad results of operations is considered by some as within the discretion of Japanese physicians. For the sake of giving patients “hope” based on their operations “successfully executed”, Japanese physicians tend not to tell the truth of bad results of operations unless the patient asks: Please tell me even if the outcome of the operation is bad, because I want

to know the truth. And I am ready to know even if the result of the operation is bad. Generally speaking, Japanese doctors are very reluctant to admit that surgery may have failed, and therefore tend not to be transparent concerning operations that have negative outcomes. Japanese doctors are prone to feel afraid that (1) any bad results of operations will affect their good standing and reputation with patients and their families and (2) their inability to cure certain diseases will reflect negatively on them.

Dr. Yamazaki felt unable to communicate the truth about the operation, the patient's wife also wanted to protect her husband from the awful truth. Addressing Dr. Yamazaki, the patient's wife insisted, "I want you to say that the operation finished without any problem" (Yamazaki, F. 1996: 216). Thus, a conspiracy of silence was reached between physicians and next of kin about the inoperable cancer.

Here, let me put the following comments: This sort of consensual agreement is very typical of conventional behaviour in Japan. The strong influence of the Japanese spouse over what physicians communicate to the patient is clearly evident. The wife insisted on protecting the patient from knowing the truth about the failure of the operation to remove the cancer.

The physicians reluctantly agreed to his wife's command / request to tell the patient that the operation had been successfully executed. The reason they acceded to the wife's request was because, in Japan, the agreement with the family of the patient is the basis of whatever the physicians tell to their patients. However, Dr. Yamazaki's personal view – as communicated in his book – is that whenever families and physicians opt to withhold the truth about a disease and its condition from a patient because (1) the disease is hopelessly incurable and (2) they are filled with sorrow and regret to have to break such bad news, such a judgement is (a) in reality a sign of not fully trusting the patient with the information and (b) a violation of the patient's human rights, by taking away the patient's ability to make his or her own decisions based on full and true information (Yamazaki, F. 1996: 220-221).

Here, let me add there have been many legal suits in Japan by the family of patients right after the patient's death, because physicians did not ascertain the family's wishes concerning the patient's treatment. I wonder if the Japanese family should be educated about how important it is to tell the truth to the patient. After telling the truth, the patient and family together begin to think further about how to deal with the bad news about the cancer rather than simply waiting for the patient to become aware that the operation might have failed. Such kind of waiting time is genuinely so silly that no one can help the patient at all in terms of cure from the disease of the patient.

Four weeks later, the patient was discharged from the hospital just like a normal patient who has gone through a stomach operation. Because the patient recovered as normal after the operation, the physicians lost the opportunity of telling the truth [meaning the bad result of the operation to the patient] (Yamazaki, F. 1996: 217). The patient left the hospital believing he would be cured pretty soon. He visited the hospital regularly, once in every two weeks, as an outpatient, and returned to work. He said to Dr. Yamazaki, “I am glad to have had the operation, my work has been somehow well” (Yamazaki, F. 1996: 217). Having heard his patient’s positive feedback of the operation, Dr. Yamazaki decided not to tell him the truth of the operation.

Regarding the recurrence of the cancer, nine months after being discharged from hospital, the patient began to report a decrease of appetite at meals and other symptoms. The X-ray of his stomach showed the increase of the cancer. Dr. Yamazaki, once again, could not tell the patient the truth that the cancer had spread. Instead, Dr. Yamazaki, with a very vague explanation, said to him, “You once again need to be hospitalized for the treatment” (Yamazaki, F. 1996: 217 – 218). What made Dr. Yamazaki have a surprise was that the patient seemingly did not think of the possibility that the cancer could re-occur in the future, although he certainly agreed to re-hospitalization (Yamazaki, F. 1996: 218).

Based on his numerous experiences with many patients whose mental as well as physical health deteriorated due to having been caught between (1) the explanation untruthfully given and (2) hope being in vain, Dr. Yamazaki wondered if this patient also would not be the exception meaning to become the same situation as any other patients with being caught between (1) the false truth told and (2) hope not to become reality. Dr Yamazaki’s perspective is that patients who are told about their terminal disease are able to cope with the bad news, once they have recovered from the initial shock, and can then resolve to make the most of the remaining time with their loved ones:

Those patients whose truth of disease was told by me unexceptionally have regained their mental and physical health, although some of my patients temporarily have got a strong shock, once I told them the truth of their disease. Thus, I know such patients whose diseases have been told by me have spent their valuable time with their families compared with the merely deteriorating patients whose truth of disease was not told (Yamazaki, F. 1996: 218 – 219).

Thus, Dr. Yamazaki decided to have a meeting with the patient’s wife and the nurse in charge of him, in the afternoon of a Saturday, after the patient’s re-hospitalization. Dr. Yamazaki told the patient’s wife about her husband’s disease and the high probability that he would never be discharged from the hospital. Dr. Yamazaki asked the patient’s wife whether she had been

continuously telling him the untrue disease condition. The wife said, “Since my husband’s disease has come to this serious stage, I think it is all right to tell to my husband about the true name of his disease and his present condition [from the physician], because it is sad for him in his 40s to become weakened until death without knowing any truth of his disease. If the time left is very short, I wish him to spend it however he wants, as I know he is the person of keeping anything tidy and in a well-ordered manner” (Yamazaki 1996: 219).

Regarding the difficulty of truth-telling in reality, Dr. Yamazaki mentioned the change of the wife’s heart, because in the early morning of the next week’s Monday, the wife called up to the ward of the hospital where her husband had been hospitalized and said not to tell the truth of disease to her husband, despite the agreement she had reached between her and the staff members of the hospital about telling him the truth. In order to ascertain what she really wanted to say, Dr. Yamazaki called the wife to understand directly what she was thinking. The wife said, “To tell you the truth, yesterday or the last Sunday, we had the meeting of parents and brothers regarding the problem of telling the truth of disease to him. In that meeting, except for me, no one agreed to tell the truth of disease to him” (Yamazaki 1996: 221 – 222). Dr. Yamazaki said, “I think it is better to make telling the truth a pending issue [i.e. to delay telling the patient the truth, for the time being]. Let’s keep thinking of what is the best and the number one way for him, while having a meeting [with you] whenever necessary depending on the psychological change that will accompany the deterioration of his disease” (Yamazaki 1996: 222).

After gastroscopy treatment for two months, the patient’s intake of food improved and his weight increased. A few days before his discharge from hospital, in a meeting with the nurse in charge of him, Dr. Yamazaki said to the patient:

Congratulations on being discharged from the hospital! The gastroscopy treatment has effectively functioned, as you managed well to cope with such treatment. By the way, I believe that your present condition is the best in terms of your disease. Of course, you may become much better. Or you might get worse causing you to be hospitalized once again. And so, please take good care of yourself in daily life, while remembering what I’ve said right now. Please use your precious time with special care. And good luck!!! (Yamazaki, F. 1996: 223 – 224).

The patient replied, “I totally can understand what you have told me. I really appreciate your kind and thorough explanation about my disease and the related suggestions on my everyday life. From now on, I will try to change my own life to my family to be focused, as I have been workaholic indeed” (Yamazaki, F. 1996: 224).

Three months later, he was re-admitted to the hospital, due to much greater deterioration of weight caused by no intake of food. After one month of re-hospitalization, his condition had deteriorated even further and he was seemingly out of patience. His strong complaints to the nurse, although no complaint was uttered by him to the medical provider, triggered Dr. Yamazaki to recognize the deterioration of his mental condition. Dr. Yamazaki felt terribly sorry for the patient in this mental state, compared to his sincere personality in terms of combating the disease and in his conversation with the physician (Yamazaki, F. 1996: 225). Thus, Dr. Yamazaki said to his wife:

I believe that your husband has been weakening mentally as well as physically. He can never figure out the huge gap between (1) what we have explained as the truth of his disease and (2) what is really going on in terms of his disease driven condition. I believe that he has no idea of where he is located at the present moment. He is in the dubious or ambiguous condition, having to decide between (1) whether to keep on having hope by believing in what we told him and (2) whether to believe that he has been told a lie or false truth, because of his own daily experiences of physical deterioration. I wonder if the time has come to tell the truth of his disease (Yamazaki, F. 1996: 226).

Her seemingly waiting for Dr. Yamazaki's statement, his wife said, "I agree with you about telling the truth of his disease. So far I have been worried, but I wish to believe in my husband's strength [to cope, i.e., to acknowledge and come to terms with the truth of his disease]. Even if my husband begins to struggle with how to understand the truth of his disease, I will try to support him" (Yamazaki, F. 1996: 226). Dr. Yamazaki said, "We too will support him as much as possible. He can manage to accept the truth told, I believe" (Yamazaki, F. 1996: 226 – 227). Thus, truth-telling to him is finally agreed among all concerned (Yamazaki, F. 1996: 227).

The meeting to tell the patient the truth took place with him, his wife, Dr. Yamazaki, the nurse in charge of him, and the head nurse of the ward of the hospital. After explaining his disease driven condition with various data, Dr. Yamazaki said to the patient, "What do you think of your disease at the present moment?" (Yamazaki, F. 1996: 228). The patient said, "Although you seemingly have given me many treatments, I can hardly eat anything. Therefore, I believe no improvement has been made" (Yamazaki, F. 1996: 228). Dr. Yamazaki, by honestly acknowledging the fact, said, "We also believe so" (Yamazaki, F. 1996: 228). After a while, Dr. Yamazaki said to the patient, "What makes you suffer is the disease on which we did have the operation earlier. Do you know the name of the disease?" (Yamazaki, F. 1996: 228). The patient said, "I wonder if my disease was a stomach ulcer" (Yamazaki, F. 1996: 228). Dr. Yamazaki said, "Do you honestly believe so?" (Yamazaki, F. 1996: 228). He said, "Well... no, Doctor. I know...."

A few seconds later, he resumed his own posture and said, while gazing at me [Dr. Yamazaki] with his determined eye, “I see right now the truth, although I’ve wanted not to have had such disease. I am terribly sorry for not understanding well and becoming irritated a bit. I’ve been wondering why my disease has not been getting better. Would there be no possibility of operation?” (Yamazaki, F. 1996: 228). Dr. Yamazaki said, “No operation is possible, I believe” (Yamazaki, F. 1996: 229). He strongly said, “I will try to work hard myself and that would you please help me out with any treatment possible” (Yamazaki, F. 1996: 229). Dr. Yamazaki said, “I wish to do treatment of your disease as much as possible. Please keep having hope. This battle of your disease might turn out to be the battle of no win. With that in mind, I wish you to work hard!” (Yamazaki, F. 1996: 229). While noticing his wife to begin to weep, Dr. Yamazaki said, “Now we have come to the situation where there is not a lie between us. So, please feel free to honestly tell us anything without any hesitation. We all are determined to support you as much as possible” (Yamazaki, F. 1996: 229). Then, the patient said with a smile lastly, “”Doctor, Please keep on telling me the truth of my disease from now on. I will try to work hard” (Yamazaki, F. 1996: 229). Then, he stretched his hand to shake hands with Dr. Yamazaki. Thus, “We had our shake-hands firmly exchanged” (Yamazaki: F. 1996: 229). At the final moment of his life, Dr. Yamazaki followed the wishes of the patient and the family by injecting a drug to reduce pain and suffering in a light sleeping condition with his consciousness to be lessened, not necessarily to intend to let him die pretty soon.

Right before using the drug to him, Dr. Yamazaki determined to tell the following message to him and said, “Now, I am going to inject the drug. I believe this drug will certainly help to relieve your pain and suffering. Or you might begin to have a deep sleep. If that is the case, you might not be able to talk any more. Is that all right with you?” (Yamazaki, F. 1996: 238). Then, he looked at Dr. Yamazaki and nodded. Dr. Yamazaki said, “Dear Mr. Y, I really want to say to you before you are going to sleep. I believe it was truly good to have met you. I have been respecting you. You have been a wonderful person!” (Yamazaki, F. 1996: 239). He then put a smile – even under the difficult condition of his breathing – and said, “Doctor, Thank you very much. I also believe it was good to have met you, Doctor.” (Yamazaki, F. 1996: 239). And he closed his eyes. When Dr. Yamazaki said, “Right now, I am going to inject the drug,” he nodded, while his eyes were shut (Yamazaki, F. 1996: 239).

As the response to Dr. Yamazaki who asked his wife whether or not a medical machine, i.e., respirator, should be used to artificially move his heart for a while, his wife said, “I want him to die quietly as it is his present condition” (Yamazaki, F. 1996: 239 – 240). Thus, his wife and Dr. Yamazaki reached the agreement to let nature deal with his final moment. Dr. Yamazaki said to

the family, “Please tell to him whatever you really want to say right now, because hearing is supposed to be only kept up until the end of life of patient. He will certainly feel glad to hear your feelings, although he might not express any response. Your feelings will certainly be heard [by him]” (Yamazaki, F. 1996: 240). His daughter aged 16 said to him, “Dad! You have done well indeed!” (Yamazaki, F. 1996: 241). Having heard her say that, Dr. Yamazaki acknowledged the fundamental importance the patient had within his family [as the father of two children and a husband, together with the key role duly executed by him up until now] (Yamazaki, F. 1996: 241).

As his candid confession, Dr. Yamazaki acknowledges this patient becoming his own intimate friend, not just his patient (Yamazaki: F. 1996: 236).

Dr. Yamazaki strongly believes that what is desperately needed for the terminal cancer patient is the mutual loving and trusting relationship together with their sharing the same feelings between the patient and the persons related to the patient in order not to make the patient feel his/her own loneliness. That is to say, what Dr. Yamazaki can ascertain out of his experiences with many patients is that such a loving, trusting, and sharing relationship between the patient and the persons surrounded by the patient mutually acted out can help the patient thoroughly keep on living, while coping with his/her disease, certainly overcome death, and surely accept death, even without having religion (Yamazaki, F. 1996: 256).

Some comments on this patient’s case are necessary. The case shows the desire on the part of the physicians and the wife of the patient to offer some hope to the patient. But offering hope is here placed in conflict with truth-telling. Physicians in Japan do not tell the truth of bad news of operation in order to allow patients to retain hope. However, by keeping the truth from the patient, he or she – the patient – is offered false hope. The doctor’s responsibility is to tell the truth of bad news in order to create transparency concerning the patient’s disease. Once the truth has been told, the physician and the wider hospital team (including the chaplain, if appropriate) can reflect on how to solve the issues contained within the bad news in partnership with the patient and family through interaction and communication.

## **2. Good practice regarding truth-telling in medical settings in Japan**

Since the 1980s, highly motivated individual Japanese medical doctors have been expressing their own candid viewpoints on how truth-telling and information disclosure should be created for the patient at the end of life even under the medical tradition of Japan: paternalism. The following are

the most influential and succinctly stated ideas of the enlightened individual Japanese physicians' confidence found in their books and/or medical journals so far.

On whether the truth should be told to the patient, Dr. Kono in Tokyo confessed that:

Based on my approximately 20 years' experience of clinical practice as an internal physician, I have never heard any bad results of cancer clearly told, despite thorough preparation of medical staff in terms of psychology, mental and physical aspects of medicine, and any other related fields ... Almost all people wish to have peace, no pain, and humane life at the end of life. In order to actualize such a death, I argue truth-telling should be executed not only with the name of the disease, but with the quantity of life that remains, for the sake of (a) helping the patient achieve the work not yet finished and (b) helping the medical staff act out much better medical treatment for the patient at the end of life. Because of the most serious two problems: the patient has extremely limited time only left and the patient is presently in the terminal stage, I believe and wish to actualize the true human relationship of open minded attitude as the engine of relations, not any lie rooted in a false human relationship. If any help and support are available, a human being can overcome any kinds of adversities. Even death with peace is possible through religious faith (Kono, T. Showa 63<sup>rd</sup> year, 1988: 45f. (855f.)).

I wish that physicians like Dr. Kono, who analyzed the situation not only from the physician's perspective, but from the patient's perspective, with deep thinking of and consciousness around the experience of death itself, would become the role model of young physicians destined to take up the vocation of medical practice in Japan in the 21<sup>st</sup> century and beyond.

In the exceptional case where the patient has already known the terminal cancer, Dr. Tokunaga said, "without concealing cancer, the patient, the family, and the medical staff members can exchange their own views and/or feelings. As the result, much better treatment is actualized for this patient" (Tokunaga, S. 1982: 182). What should be learned from Dr. Tokunaga's book are three points: (1) the courage of this patient to accept terminal cancer, (2) the cancer patient is trying to live as normal as possible, and (3) the positive behaviour of Dr. Tokunaga and/or other medical staff members in learning from this patient and/or the family. This book, published in 1982 in the fairly early time of openly talking of cancer in Japan, offers the real patient's and the family's experiences as the vehicle for ordinary Japanese people to tackle whether terminal cancer would be directly told to the patient.

Withholding information on diagnosis from patients reveals Japanese medical practice in comparison with its Western counterpart. Telling truth of cancer is seemingly case-by-case in Japan, as Dr. Asai states, "No standard criteria or widely accepted methods predict a patient's



ability to cope with this serious situation [cancer-diagnosis is told]. Leaving the decision to physicians' impressions risks being biased by the physicians' own perceptions of cancer and death and own personalities" (Asai, A. 1995: 37). He continues, "It would be paradoxically paternalistic for physicians to convey a diagnosis of cancer to patients who stated that they did not want to be informed ... (Omit 8 lines). Therefore, a patient's wish to know or not to know the truth is the most important factor in determining disclosure" (Asai, A. 1995: 37). "Patients vary from one another even when their cultural origin is identical" (Asai, A. 1995: 38). In order to create the appropriate strategy on how to directly ask questions to patients, Dr. Asai points out the need for guidelines to change clinical practice of Japan with the following considerations: (1) the doctor should objectively think of his/her own practice on truth-telling, (2) the patient's autonomy should be acted out, and (3) the intra-cultural differences of the individual patients should be clearly checked out.

Concerning morphine treatment and terminal cancer patients, Dr. Miyanari, a specialist in morphine treatment, states that the treatment of cancer patients at the end of life is to chiefly deal with the pain of the terminal cancer patient through applying morphine, as stated:

Cancer treatment is based on relationship of trust between the patient and the medical doctor. To establish trust, the true information should be given to the patient from the medical doctor. We have the policy of basically telling cancer to all the cases ... So far, we have recognized in numerous cases that to delete the pain of the patient is absolutely essential to the improvement of the quality of life of the patient. Telling cancer is important for the sake of the patient to recognize the need for effective treatment (Miyanari, N. 2002: 185f.).

Based on Dr. Miyanari's comments, I can verify the characteristic of Japan as the result driven society by focusing on the goal and/or effect, not the cause, of the patient's quality of life. Thus, telling cancer to the patient is justified as the vehicle of the result anticipated: the patient's beginning to take effective treatment. Here, one may say that, throughout the history of medical practice in Japan, the priority of physicians has not been their own genuine intention to truthfully communicate to their patients, but rather their consideration of the result, as the research of Dr. Tanida indicates below to only tell "early or curable cancer":

The majority of doctors who added comments said that truth disclosure was desirable but it should be practiced with thoughtful consideration of the background of the patient and [the] family. Especially, the role of the family was pointed out to be important in both the "tell" and "do not tell" sides of the issue, and approval or objection by the family played a key role in the doctors' decision. Strong objections were few, and some doctors who said "do not tell without exception" tried to give information to patients in a roundabout way. One

physician noted that “early cancer is not always curable, therefore the truth should not be told under any circumstances.” The answer of “do not tell except on rare occasions” indicated that the exceptions were mainly in cases of early or curable cancer (Tanida, N. 1994: 53).

Dr. Tanida also stated below as the caution against giving false hopes to the patient of no recovery.

Except for any achievable goal of the patient’s disease discovered as advisable as to give hope and encouragement to the patient, realistically speaking, false hopes should not be given to the patient, if no recovery is envisaged. (Tanida, N. 2003: (683) 083).

Thus, the effects of truth-telling are the main consideration of physicians in Japan. Rather than good motivation, it is the anticipated result that is the number one priority not only of Japanese medical doctors, but of all aspects of Japan, as it forms the hidden agenda of Japanese society.

Since the 1990s, the National Institute of Cancer hospital in Japan has been the beacon of good medical practice on telling truth of cancer. The approach to truth-telling at the hospital includes how to tell the truth and how to further support the patient, on an individual patient basis. The “Gan Kokuchi Manual” (“The Manual of Telling Cancer”) of the hospital of the National Institute of Cancer, used by the hospital’s staff, has been out on its website since the 2<sup>nd</sup> of December in 2004, as the revised version of the previous manual dated on the 18<sup>th</sup> of February of 1997. The manual covers the following important aspects:

(1) The principle of the hospital is to tell to the patient; (2) The same physician is expected to help the same patient from the first consultation to the beginning of treatment. Along with the human relationship and trust between the patient and the physician are being created, truth-telling is to be executed to let the patient decide with certainty among alternatives of treatment; (3) The patient’s feelings and privacy are considered, whenever truth is told, i.e., telephone is not accepted for telling truth; (4) Truth-telling is given, once information is known. Then to clearly tell, once the specific diagnosis is confirmed; (5) The physician’s one-sided talk of the patient’s truth is not allowed, because the condition of the patient should also be considered; (6) Physicians are in the position of giving both hope and despair to the patient. Thus, they should be careful with their choice of words, and not to say, “You [the patient] have advanced cancer. Thus, I [the physician] cannot do anything. There is no treatment available”.; (7) Telling truth to outpatients is to be made with ample time of explanation duly taken and any further needs also to be considered, i.e., a psychiatrist’s help may be needed, if the patient has psychological problems; (8) Japanese patients take reserved attitudes towards Japanese physicians or even to have fear in some cases. Since Japanese

patients ask their questions to Japanese nurses, [Japanese] physicians need to learn their patients' feelings and claims through [Japanese] nurses; (9) Truth-telling may require the repeated explanations and/or step-by-step approaches of telling disease; and (10) To think the patient's perspective is expected without simply sticking to the physician's judgement. Regarding how to interact with the family of the patient, the patient is the first priority to tell truth, not the family of the patient. But when cancer is diagnosed, the family is expected to be informed to take the pivotal role in the patient's treatment. If the family faces mental problems right after the patient's diagnosis is told, staff members are to let the family contact a psychiatrist.

The above mentioned summary of the manual is an amalgam of the East, Japan, and the West: "kokuchi" ("truth-telling in Japan under the tradition of paternalism") and "informed consent" ("the original concept and medical practice of truth-telling in the USA"). Thus, good medical practice already proven in the West has been working effectively even in Japan.

Dr. Michio Ogawa, Vice President of Kumamoto University in Kumamoto Prefecture, Kyushu, Japan, states that no manual can teach how to tell the truth of disease to the patient. The reason is that the disease of each patient differs from any other patient's disease. Prognosis-telling-wise, with his cautious statement of, "regarding how long the patient lives, no prognosis is told, except in very rare cases" (Ogawa, M. 2002: 18), Dr. Ogawa, based on his clinical experience, suggests the following seven points on telling the truth to cancer patients.

1. Telling truth can only be made at the place where the privacy of the patient is protected.
2. Do not tell truth in a hasty manner, but take enough time to tell to the patient.
3. Ask the patient of (a) how much truth is known on the disease of the patient and (b) what kind of wish and hope the patient has had on the disease being treated.
4. Tell truth on a step-by-step basis, while the physician monitors the response of the patient to the truth told by the physician.
5. Regarding the patient's condition, tell truth to the patient who would be able to continue to have hope and always take a positive attitude towards the disease.
6. Tell clearly the physician has determined to take the duty of helping the patient.
7. Never take a lukewarm attitude to the question of the patient, but give the answer directly to the patient. (Ogawa, M. 2002: 18f.)

These points mentioned above correspond in great part with the directives found in the manual of the hospital of the National Institute of Cancer.

According to K. Tsuboi, "The core argument is not whether or not to tell the truth to the patient, but the quality of truth-telling or "kokuchi" in Japanese, of how to tell the truth and then how to support the patient right after the truth is told" (2004: 22). Tsuboi goes on to point out that patient-centered medical treatment for which human rights are highly respected can only be achieved by telling the truth to the patient, the subject of medical practice. And then, the patient's

decision, based on the truth told, should be respected meaning informed consent is the essential vehicle of medical practice. Ensuring that there is no gap of information between (a) the patient and the doctor and (b) the patient and the family of the patient is the key to establishing a trust relationship among them all. Not to tell the truth to the patient at the end of life is to make the patient have no opportunity to choose how to live the life remaining, how to spend each day left, what to take as the priority, and any other issues concerned. If the patient has no honest interaction with the family, the precious time of communication of “hon-ne” (“the genuine thinking, wish, and/or feeling of the individual”) will never be created (Tsuboi, K. 2004: 22f.).

I would argue that the quality of truth-telling would be closely related to how the truth is delivered to the patient through the authentic interaction between the patient and the physician followed by another authentic interaction between the patient and the family of the patient. The practice of “i no kokoro” (“the warm-hearted, genuine, and thorough consideration of the physician about the patient’s psychology and any other issues related to the patient’s conditions, as the core of medical practice”) should be demonstrated for the treatment of the patient at the end of life, as Nabekura pointed out with the specific patient’s example (Nabekura, I. 2007: 128f.).

A study of 529 cancer outpatients indicates the preferences of Japanese patients compared with those of American patients. This study suggested for Japanese physicians to improve: (1) to let patients ask questions, in order to overcome the Japanese concept, “amae”, advocated by Doi in which people really expect the interlocutor to think of and act towards them just like they would prefer for themselves, and (2) to focus on gender, disease status, fighting spirit, and anxious preoccupation of patients (Fujimori, M. et al. 2007: 617f.).

On telling the truth of prognosis vs. avoiding patients’ hastened death, Dr. G. Kato has a new strategy. Concerning the relationship between (a) prognosis is told and (b) the need of brainstorming for both, patient and physician, to ponder how to constructively use the patient’s still remaining time, G. Kato M.D. who also has a Ph.D. in Sociology, takes a cautiously optimistic approach towards how to tell prognosis to the patient. Death is difficult to predict, due to numerous elements of prognosis fabricated among patients.

Through the facts that the patient diagnosed to live for a few months actually lived either for a few weeks or for one year, no one can say that death was told appropriately (Kato, G. 2008: 39). Dr. Kato argues what makes prognosis more difficult is the lack of education on prognosis itself in Japan compared with diagnosis and treatment (Kato, G. 2008: 40).

Prognosis of death to come shortly is not only to make the patient and the physician experience huge stress, but also to make the prognosis become a self-achieving prediction, i.e., telling the patient that death will come pretty soon is to make the patient to lose hope and to eventually hasten the patient to death, whereas telling optimistic prognosis is to make the patient of imminent death to become positive and not to lose hope even before death, and that the life of the patient is eventually prolonged (Kato, G. 2008: 41).

Regarding the relationship between responsibility of the physician to tell prognosis to the patient and the patient autonomy certainly to be acted out, if the physician does not tell the worst news, that death is just about to come, to the patient, such physician's attitude is considered as a part of paternalism (Kato, G. 2008: 41 – 42).

Even if telling the accurate prognosis is difficult, telling no prognosis would basically oppose heavily to the expectation to the responsibility of physicians as the specialized professional group (Kato, G. 2008: 42).

Finally, Dr. Kato asks whether it is possible to tell prognosis to the patient, while avoiding its effect of hastening the patient's death. He believes it is possible. What is needed for physicians to change their own mindset is that the patient's remaining life of the prognosis already told and the medical treatment & care during such time of the patient should never be judged as "the prelude to death, the defeat", but to be considered as "the precious time of many things to be solved for both of the patient & the physician".

Along with such a change of attitude & behaviour to be made by physicians, telling prognosis with its accurate prediction is to become the process to be necessary for such precious time of unsolved things duly solved both by the patient & the physician (Kato, G. 2008: 42).

I believe that Dr. Kato, with his clinical experiences with Japanese patients, has given great insights into how to face dying and death from both patients' and physicians' perspectives through considering what would be essential for the patient's precious time at the end of his/her own life. Further study on the relationship between death and prognosis is anticipated juxtaposed with interdisciplinary approach towards what exactly means to be living as the patient at the end of life and/or the human being as a whole. These issues will be explored further in chapter five.

### **3. The practice of withholding and withdrawing life sustaining treatment in Japan**

Among a variety of treatments available to patients at the end of life, withholding and/or withdrawing treatments have been pivotal problems not only to the patient and the family, but to the physician with the question of how life prolonging treatment should be used for the patient.

Thus, the following are some comments of Japanese physicians followed by the latest survey on withholding and/or withdrawing treatments in Japan.

Underlining Japanese doctors' belief in treatment at all costs, Dr. Asai states: "Japanese physicians tend not to withdraw artificial nutrition and hydration from persistent vegetative state patients" (Asai, A. et al. 1999: 302 – 308). Or, Japanese physicians are prone to have:

... [more] negative attitudes toward the withdrawal of life-support care than its withholding. On the other hand, they [Japanese physicians] favor withholding invasive life-sustaining treatments such as the attachment of a respirator over less invasive and long-term treatments such as tube feeding (Bito, S. and Asai, A. 2007: 8:7).

In order to ascertain the present status quo of Japan, the practices of withholding and/or withdrawing life prolonging treatments in Japan were investigated by the Yomiuri Newspaper in 2006 and 2008.

Concerning the 2006 investigation, out of the 685 hospitals of more than 100 beds to which questionnaires were sent, 240 responses came back discussing practices for withdrawing and/or withholding life-prolonging treatments from patients with terminal diseases. Fifty-six percent (56%) of the respondents, or 134 hospitals, stated that they had withdrawn and/or withheld life prolonging treatments (Yomiuri Newspaper, 31 July 2006). 71% of the 134 hospitals withheld and/or withdrew respirators. [This finding means that withdrawing respirators at Imizu City Hospital was not the exception.] 70% withdrew or reduced the quantity or dosage of medicines; 35% withdrew blood transfusions; and 34% withdrew blood related dialysis. All treatments were withdrawn from the patients by four hospitals (3%). The reasons for such withdrawing and/or withholding were in order to respect the wish of the family of the patient (from 89% of respondents), and in order to reflect the medical judgement of the doctor (from 70%). For 46%, the decision was left solely to the discretion of the patient's doctor, compared with 37% reporting that the decision was made by the team of medical staff members. Hospital Ethics Committees were hardly used, except by 4% of the hospitals, whose answers indicated the desire for their decision-making process to be transparent.

Regarding legal aspects, 26% of responding hospitals stated that they had unresolved legal issues, 26% stated they had no medical problems, although it might be problematic legally, and 20% stated they had no problem at all. More than 70% of the 240 hospitals wanted legal regulation of treatment at the end of life including the withdrawal of life prolonging equipment used throughout Japan. 60% preferred to have government guidelines.

While 134 hospitals (56% of hospitals) stated that they had withdrawn and/or withheld life prolonging treatments in 2006, this figure dropped to 31% between 2007 and 2008, as reported on the 26<sup>th</sup> of July 2008 in the Yomiuri.

As for the 2008 survey, 117 hospitals out of 379 hospitals (the response ratio of 32% of the original total 1191 hospitals of more than 300 beds throughout Japan) responded in 2008 stated that they withdrew and/or withheld life prolonging treatments from terminal patients. The voluntary feedback reports from those 117 hospitals gave information on 1902 patients' treatments: 395 involved withdrawing and 1507 involved withholding. This article also states that at 40% of the 117 hospitals, doctors made the decisions, at 19 hospitals (16%) only one doctor made the decisions, and 28 hospitals (24%) required more than two doctors to make any decision. These figures reveal that the government's guidelines from May 2007 requiring decisions of treatment at the end of life to be made by multiple-professionals-based-team have not yet been practised throughout Japan.

46% of the 117 hospitals admitting withholding and/or withdrawing treatments also pointed out the problem that more patients had difficulty finding places for long term medical care, due to the reduction of total beds for long term patients. 39% of the 117 hospitals reported that some patients actually received no treatment, because of the increase of medical treatment charges which elderly patients had to pay.

Here I would argue on the following points. Such a low response rate of 32% (with only 379 out of 1191 hospitals answering) raises questions about the wider applicability of the findings. In addition, the 2006 and 2008 investigations cannot be compared easily, because they used different parameters: in 2006, the newspaper looked at hospitals having more than 100 beds, while the 2008 study looked at hospitals having more than 300 beds. However, one similarity between 2006 and 2008 was the low feedback rate of the hospitals in Japan: 35% in 2006 and around 32% in 2008. These low rates of reply tell the fact of how narrow the consciousness of Japanese hospitals remains about voluntarily giving their own data to the public. Many hospitals in Japan seem to be timid about revealing data concerning end-of-life treatment.

As one of the significant lawyers in Japan on the legal aspect of medical treatments for patients at the end of life, T. Kuroyanagi points out the intersection between legal and medical problems for contemporary Japanese patients at the end of life. He proposes there be a government survey of patients at the end of life on withholding and/or withdrawing life prolonging treatments in Japan, and he advises medical professionals' groups and associations to urgently create guidelines on withholding and/or withdrawing life prolonging treatments from

patients (Kuroyanagi, T., 2003: 237). To some extent, guidelines have been drawn up, but a gulf still exists between prevailing attitudes and/or practices and guidelines.

In terms of Japanese blogs, numerous complaints and struggles of patients and their families are available with their own real and vivid explanations on the following two critical problems: (1) how much telling truth from physicians to patients and their families has been executed in the individual patient's case and (2) how withdrawing and/or withholding life prolonging treatments would and/or should be used for their loved one, the patient.

The response of the government to the worries and concerns of patients and their families has been too slow, causing severe headache and heartache to limitless patients and their families at any given time. The Government of Japan and the medical community of Japan should act to eradicate such a bad habit of always publishing guidelines too late. Such guidelines should have been created and/or published much earlier, i.e., more than 20 years ago, when Japanese people were struggling with how to deal with medical technology for maintaining the quality of the patient's daily life. Under consensus prioritized Japanese bureaucracy, so called "guideline" is merely a notoriously late suggestion for what society has already taken on board.

Whether ICU (an Intensive Care Unit) would be appropriate for telling truth to patients was investigated, with questionnaires, by the ICU nurses of 79 facilities in Japan. The results are: (1) ICU patients are often unconscious with their wishes unknown: "Many patients in the ICU are sedated and their voice cannot be heard" (Kinoshita, S. 2007: 654); (2) treatment decisions are usually made mainly by the family, even if the patient has expressed his/her wishes: "Even though patient B had said he did not wish to undergo surgery, the patient's family was persuaded by the physician to permit it ... the patient eventually died after surgery" (Kinoshita, S. 2007: 654); and (3) ICU is considered unsuitable for end-of-life driven care, because the ICU is geared towards saving life. Most patients in ICU want to recover and get out of the hospital to resume so-called "normal life". Thus, the patient's desire of not being treated conflicts with the ethos of the ward. One respondent stated, "The patients are surrounded by machines, and there's no feeling of freedom. I don't think the patient can feel at peace. It's not a place where I would want to die" (Kinoshita, S. 2007: 655). Thus, the study concludes that ICU is inappropriate for patient-centered treatment at the end of life.

#### **4. Lawsuits in Japan on patients at the end of life**

Since the latter part of the 20<sup>th</sup> century, the newly emerged high technology has been pushing medical practice to prolong patients' lives in particular. Thus, a gap has been created between (a) the latest medical practice of the patient's life at the end of life mechanically prolonged and (b) the



tradition of law on death and dying in the medical context. In Japan, the intersection and co-operation between medicine and law to help solve the conundrum of patients at end of-life have not yet been established up to the level of the West, although prosecutors have begun to chase doctors' mal-practices.

In Japan, there have been two kinds of notorious mal-practices claimed on patients at the end of life: (1) euthanasia driven mal-practices originally claimed by a 3<sup>rd</sup> party or not by the family of the patient and (2) telling-truth oriented mal-practices originally claimed by the family of the patient or not by the 3<sup>rd</sup> party. These will be discussed below. In both types of mal-practices, it will become clear that their causal roots lie in the lack of thorough interaction between the patient / family and the physicians, and that the reason for this lack of interaction is the Japanese tradition of paternalism.

The euthanasia-based cases occurred in Tokai University Hospital and in Kyohoku Hospital in Kyoto, although, in reality, there were many other euthanasia driven mal-practices throughout the history of medical practice in Japan, prior to these hospitals of Tokai University and Kyohoku in Kyoto called an "accident" by the media of Japan.

#### **4.1 Euthanasia driven "accidents" at Tokai University Hospital and Kyohoku Hospital**

In Japan, two very notorious euthanasia driven accidents are "Tokai Daigaku Byoin Euthanasia Jiken" ("The euthanasia driven accident of Tokai University's Hospital") and "Choritsu Kokuho Kyohoku Byoin Euthanasia Jiken" ("The Euthanasia driven accident of Kyohoku Hospital in Kyoto").

The Accident of Tokai University's Affiliated Hospital took place on 13<sup>th</sup> of April in Heisei 3<sup>rd</sup> year, 1991, when Dr. T. injected drugs into a comatose male patient to cause his death by heart attack (Hoshino, K. 1996: 86). The verdict was delivered on 28<sup>th</sup> of March in Heisei 7<sup>th</sup> year, 1995, at Yokohama District Court (Hoshino, K. 1996: 37 – 38). The Japanese media reported the Tokai University-affiliated Hospital case as "active euthanasia". However, the case is not active euthanasia, because the patient was comatose and made no request for active euthanasia.

The Accident of Kyohoku Hospital in Kyoto occurred when the head of the hospital injected a muscle softening liquid into a male patient with terminal stomach cancer to cause him to die on 27<sup>th</sup> of April in Heisei 8<sup>th</sup> year, 1996. The media started reporting the case on 6<sup>th</sup> of June in Heisei 8<sup>th</sup> year, 1996. Kyoto Police began their investigation right after the media coverage (Hoshino, K. 1996: 96).

These two cases terribly reveal Japanese mal-practices of patients at the end of life, i.e., strong paternalism among some Japanese physicians, the failure to tell the truth to patients and their families, and the failure to follow the wishes of patients and their families.

In terms of media coverage, the media of Japan always put the same stamp of “euthanasia driven accident” not only on these notorious cases, but also on any other uncertain death oriented mal-practices, because many Japanese reporters of Japanese newspapers do not know the differences between (1) “euthanasia” and (2) “dying with dignity” (“songenshi”), as Dr. Kotori, one of famous blogs in Japan, wisely mentioned the lack of knowledge of these differences among Japanese newspaper reporters.

In here, for the sake of succinctly pointing out the differences in meanings between Japanese and English, the expression of “euthanasia driven accident” means in Japanese the case of death as “euthanasia” (“anrakushi”) which happened “all the sudden” meaning “jiken” (“accident”). In Japanese media, the term “accident” is always used in the headline of many newspapers as the eye-catching word of the readers as quickly as possible, as well as indirectly telling the readers something deadly serious occurred out of the blue.

Dr. Hoshino discussed these notorious “anrakushi” (“pseudo euthanasia”) cases with their similarities. In both cases, the decision of ending life was made by the physician alone, because (1) no requests of the two patients to end their lives were obtained by the physicians and (2) no consents of the two families to end the patients’ lives were received by the physicians. In both cases, no cancer diagnosis was told to the patients. No adequate treatment was given to either terminal patient, and no physicians checked whether pain was caused by the lethal injections. In both cases, death was imminent from unrecoverable cancer. (Hoshino, K. 1996: 97). Some differences between the notorious cases are shown below, based on the summary provided by Dr. Hoshino, K. (1996: 97 – 98).

#### **The differences between Tokai University’s Hospital and Kyohoku Hospital**

	Tokai University’s Affiliated Hospital	Kyohoku Hospital in Kyoto
Human relationship between the patient and the physician	Short relationship of only 13 days when the patient died.	Long relationship of more than 20 years.
The physician’s status	an assistant physician transferred from an affiliated hospital.	The head of the hospital, and another physician was in charge of the patient.
Relationship between the hospital and physician	Not long relationship between the physician and the hospital.	As the head physician of the only General Hospital for 7,000 inhabitants, he was respected by people of the mountain city, Kyohoku.

In both cases, the abuse was revealed by anonymous whistle blowers. In the case of Tokai University's Hospital, a nurse was responsible. Concerning Kyohoku Hospital in Kyoto, an anonymous person telephoned to complain. Dr. Akabayashi identifies these infamous cases as so-called "mercy killing cases" (Akabayashi, A. 2002: 517 – 527), with his comments that these abuses were in part due to the Japanese problem of "the lack of detailed guidelines to direct physicians as well as insufficient consulting and monitoring mechanisms" (Akabayashi, A. 2002: 521).

Regarding guidelines, Dr. Hoshino comments: "what Japan urgently needs to learn as the result of Tokai University's Hospital is to create succinct guidelines of: (1) medical treatment and (2) end-of-life oriented ethics, based on expert-driven standards, in order to be practically and efficiently acted out at medical settings in Japan" (Hoshino, K. 1996: 269).

The real pivotal problem of medical practice in Japan, revealed by these cases, is that every treatment by the physician to the patient is carried out under the discretion of the physician without any intervention or consultation of legal specialists of medical ethics, while the patient at the end of life is still alive. In Japan, the process of how to treat the patient at the end of life has either not been valued or been neglected frequently. Thus, what Japan should learn from the West is that specialists of medical law and medical ethics must discuss with the physician and the patient / the family regarding how to help the patient obtain the ethically appropriate treatment at the end of his/her own life.

#### **4.2 Truth-telling driven mal-practices claimed by the families of the patients**

The second classification of law suits in Japan **concerns** mal-practices involving a physician's failure to communicate the truth of disease to the patient and/or family, as claimed by the families of the patients. The following are two tragic cases reported most recently.

##### **Case 1: Failure in telling diagnosis and physical examinations of patient A**

This law suit concerns negligence with regard to not telling the truth of the patient's disease, not explaining the details, and not executing many physical examinations to the patient. The verdict was made on 11<sup>th</sup> of January in 2002 at Muroran Branch Office of Sapporo District Court in Hokkaido. In the middle of the 1980s, the patient, A, was switched between two hospitals at different times depending on the patient's condition.

Then, the patient was hospitalized once again at one of the two hospitals in November, 1989, but A died suddenly one month later. In the certificate of death, cholangio cancer was written as the cause of the patient's death. The family of the patient began a law suit on the basis that no truth had been told of the patient's diagnosis and treatment, no further detailed explanations of the

patient's disease, and insufficient examinations had been made to ascertain the patient's disease, even though the physicians of the two hospitals had already known the truth of the patient's disease, cholangio cancer.

The main part of the verdict was to find no negligence on the part of the medical doctors regarding truth-telling and their responsibility to provide explanations to the patient. Commenting on the case, Mr. Akita, the Professor Emeritus at Hosei University in Japan, said:

What the verdict pointed out as the recognition in this case is not the recognition based on medicine and/or medical treatment, but the recognition based on law. In other words, the recognition of this case is the consciousness of legal standard and/or rule on whether or not the medical doctors would act out against legal responsibility of telling the truth to the patient (in the event of the medical doctors' being against the law, legal duty of the medical doctors is to come up as the responsibility of the medical doctors) ... In this case, the reason why the medical doctors did not tell truth and other explanations to the patient was based on no clear confirmation made among the medical doctors of the patient's cancer. Thus, this verdict judged as no acknowledgement that no telling truth & other explanations to the patient are to become against the responsibility of the medical doctors (Akita, N. 2004: 45).

## **Case 2: Failure to tell the truth - terminal lung cancer - to both Mr. P and family**

This law suit was summarized by Mr. Naoyuki Isogawa, the Professor of Legal Research at the Graduate School of Kyushu University. This case is about Mr. P., a terminal patient, with lung cancer (aged 77 at time of death) in the years from 1990 to 1991. The patient and the family of the patient were not told the truth about the patient's cancer by the medical doctors of the hospital of the prefecture. When the patient moved to another hospital, 6.5 months before his death, the family of the patient was told about the terminal lung cancer of the patient, whereas the patient died without ever being told.

Thus, the claims of the family of the patient were that the medical doctors did not tell the truth about terminal lung cancer to both the patient and the family, and that huge mental pain and suffering were created for the patient and the family, due to their being given no prognosis of the time left of the patient in order for them to prepare in any appropriate way. The total sum of 19,000,000 yen was requested by the patient's family (Isogawa, N. 2003: 53f.).

The process of this law suit, begun by the family of the patient (the wife of the patient and the three children of the couple), has three episodes. A first verdict, made at Akita District Court on the 22<sup>nd</sup> of March in 1996, allowed for a wide range of discretion for the medical doctor in telling the truth about terminal cancer to the patient in comparison with any other medical conduct, and that resulted in the refusal of the claims of the family of the patient. The second verdict, which

took place at Sendai High Court on the 9<sup>th</sup> of March in 1998, accepted partially the claims of the patient's family, judging that the doctor was negligent for not telling the truth of the patient's terminal cancer to the family of the patient, but continued to accept that not telling the truth about terminal cancer to the patient was within the discretionary power of the medical doctor.

The third and final verdict, delivered at the Supreme Court of Japan in Tokyo on the 24<sup>th</sup> of September in 2002, consisted of two main parts: First, the medical doctor should contact the family of the patient, and should investigate whether or not the family members of the patient seem all right to tell their loved one the truth about terminal cancer. When the doctor's judgement is made that it is appropriate to tell the truth to the family members of the patient, the medical doctor has the responsibility to tell the truth about the patient's diagnosis and other related issues to the patient's family members. Second, while understanding that it is the medical doctor's decision to discern the appropriate timing to tell the truth about the diagnosis to the patient's family, the cooperation and consideration of the patient's family, as much as possible for the patient's wellbeing throughout end-of-life based treatment, should be thought of as the valued interest, when determining the legal protection of the patient. (Isogawa, N. 2003: 53f.).

It is noticeable that even a slow change has been taking place between (a) the history of clinical practice in Japan, where the truth was hardly ever told to patients and their families and (b) a new wave of telling truth to the patients. As Isogawa writes,

in the past, Japan had no custom of telling cancer directly to the patient ... However, in reality, the National Cancer Center driven Hospitals of Japan have been telling cancer to all the patients to actually accumulate the practice of truth told in Japan ... It would seemingly be still necessary to make the investigation for the practical standard and/or rule of Japan around the interaction between the patient's family and the medical doctor (Isogawa, N. 2003: 55).

As feedback from fellow legal professionals in Japan on the law suit of Mr. P, Judge Mizukura and Judge Koiso stated:

This verdict requires as the duty of the medical doctor to find and make contact with the family of the patient. Thus, this verdict can be said to reduce the discretion of the medical doctor. In Japanese society where respect for the autonomy of the patient has been developing, the standard and rule of conduct required of the medical doctor are inevitably affected. It is assumed that this kind of trend will be continued in the near future (Mizukura, Y. and Koiso, T. 2006: 81).

Another response to Mr. P's case has come from an anonymous judge named T who stated below, with the headline of: "To whom is the truth of terminal cancer told?"

The important problems not yet solved and/or to be investigated in the near future are (1) on protecting the individual privacy, whether or not telling the family of the patient about the disease of the patient would become more problematic and (2) if more difficult case comes up, the medical doctor would face the difficulty of making decisions whether or not telling truth to the family of the patient (the Judge T cited in Ogawa, T. and Paku, Y. 2006: 746(60)).

These comments appear to connect the contents of the verdict to the future of medical practice in Japan. I believe that the content of the verdict clearly reveals that Japan is not yet prepared for telling the truth of the patient's diagnosis directly to the patient. Judge Ogawa at Tokyo District Court, stated:

In this case, the issue was focused on the family of the patient not having been told about the terminal cancer of the patient. Even in this case, no judgement is made on the point of not telling the truth of the patient's cancer directly to the patient. The most crucial issue of truth-telling of cancer relates to whether or not the patient would be told the truth. Thus, regarding telling the truth of the patient's cancer to the patient, what kind of judgement the Supreme Court of Japan would create is for us to pay attention to the highest degree (Ogawa, T. and Paku, Y. 2006: 746 (60)).

Mr. Yu Paku, a Ph.D. student of Law & Politics at the University of Tokyo, mentioned that "Along with the development of medical treatment, medical practice to highly respect the patient's own autonomy & decision-making in informed consent is extremely important" (Ogawa, T. and Paku, Y. 2006: 747 (61)).

However, another response to Mr. P's law suit came from the persons at the law office of Tokyo, Japan, who stated that "as far as the law of Japan is concerned, there is no responsibility to tell truth of cancer" (Kuwabara, H. et al. 2005: 1097). This statement is made with reference to "the Manual of Terminal Cancer-based Medical Treatment and Care" published / edited by the Ministry of Health & Welfare of Japan and "Nihon Ishikai" ("Japan Medical Association") in 1989 in which the following four points were stated as important when telling the truth about terminal cancer: (1) to have the clear purpose of telling the truth, (2) to know the capacity of the patient and the family to receive the truth, (3) to have a good relationship between the medical doctor and/or other medical staff members and the patient and the family of the patient, and (4) to be able to give mental care and support to the patient right after disclosure is made.

Through reading many kinds of blogs in Japanese on current medical problems in Japan, I have been able to study the comments of dealing with medical professionals written by Japanese people based on their experiences of end-of-life treatment. It is clear that in Japan prosecutors

tend to investigate wrong actions of the medical doctor towards the treatment of the patient upon the requests by the family of the patient. Japanese doctors easily become the target of law suits.

However, in cases where the family members are in contact with the doctor about the patient's treatment, there are very few investigations by prosecutors in terms of the appropriateness of the family's request to the doctor, unless any evidence of mal-practice has come up through the patient, the patient's family, the medical doctor, and/or the specific hospital, as public interest is also considered. Thus, I believe that Japan needs to develop guidelines on how to medically and legally check the utterances of both the family of the patient and the doctor. Otherwise, Japanese patients turn out to be left alone vulnerable to any secret agreements made between their family members and the doctors in terms of end-of-life medical treatment and care.

As Dr. Asai argues, what is required is "physicians' asking their patients explicitly what they want regarding medical care" (Asai, A. et al. 1998(b): 171). According to Miyata, "at the first opportunity of providing information, a disclosure policy of giving patients full details of their diagnosis and some information on prognosis can satisfy the preferences of most patients" (Miyata, H. et al. 2005: 447).

Ideally, therefore, what physicians should do is "first [to] provide the details of the disease to their patients. Thereafter, family members should be informed, but only with the patient's consent" (Seo, M. et al. 2000: 105). I agree that the patient should be the first person to know the truth of his/her illness. The family of the patient should be secondary, based on the agreement between the patient and the doctor.

In terms of the above two heartbreaking cases of failure to communicate the truth about the patient's condition, there have been many other truth-telling driven mal-practices followed by law suits, before and after the two cases mentioned. Similar unreported cases occur in multiple hospitals in Japan. With these points considered, I would argue that Japan is far behind on decisions concerning telling terminal patients the truth, not only in the law of Japan for setting the standard of the autonomy of the patient, but also in the consciousness of medical professionals in shaping the duty of medical staff members on the soil of Japan. I also think that telling the truth is right at the intersection between Japanese law and Japanese tradition. Unless the grassroots people of Japan become aware of the importance of telling the truth directly to the patient, no change will happen in any Japanese medical setting.

Thus, I strongly believe that truth-telling oriented medical practice or information disclosure in much broader and/or general terms would eventually reveal the tangible & intangible numerous unsolved problems of Japanese society with its tradition, i.e., what Japanese ordinary people are able to digest about the concept of telling truth, how they are able to apply that concept in the real

medical context of Japan, and how they might be able to change the medical climate of Japan from the long tradition of paternalism to prioritizing the autonomy of the patient and actualizing decisions made by patients themselves.

## **5. Japanese Guidelines on the treatment of patients at the end of life**

The guidelines for end-of-life based medical treatment by “Nihon Ishikai” (“Japan Medical Association”) were not established until Feb. 2008. The end-of-life oriented stage is said to be arrived at when the following two conditions are fulfilled: (1) when the medical team with the doctors, nurses, and any other medical staff members reaches the judgement that the death of the patient is imminent or no progress is anticipated, despite the best medical efforts made and (2) when the patient or, in the event of the patient unable to make a decision, the patient’s family or representative (not only legally binding kin, but also any other person the patient trusts), has thoroughly come to understand the situation. The expression “kazoku too” (“the family of the patient and the other person”) includes any other person whom the patient trusts, as well as kin in the legal sense.

### **The four points below are needed for medical treatment at the end of life:**

- The decision that the patient has reached the end-of-life stage is made by the medical treatment and care team.
- Withholding, withdrawing, and any other changes of medical treatment of the patient at the end of life are based on the wish of the patient and cautiously / carefully judged by the medical treatment / care team on the basis of medical appropriateness and effectiveness.
- Total medical treatment and care are expected to help the mental and social aspects of the patient and the family of the patient to be maintained, while mitigating pain and any other uncomfortable symptoms as much as possible.
- No “Sekkyokuteki Anrakushi” (“active euthanasia”) and “Jisatsu Hojo” (“the help of the medical doctor to make the patient to die and/or to be assisted suicide”) are anticipated in Japan.

Regarding emergency cases of patient’s medical treatment, the discretion of the medical doctor is expected, while respecting human dignity.

## **6. Home-based care of terminally ill patients**

Many terminally ill patients prefer to follow the Japanese tradition of dying at home with family members’ care, known by the euphemism of “tatami no ue-de shini-tai” (“I want to die on the Japanese ‘tatami’ mattress”). With home-based care, the patient-doctor relationship differs from hospital-based care. With home-care, the doctor must adjust to the patient’s home environment



with almost no high-tech medical equipment is available at the beginning of the patient's care. Thus, the doctor needs flexibility and creativity about how to take care of the patient with the limited medical resources.

The doctor has to show high respect to the carers, the family members, by listening to any comments and requests, because the home is now the "hospital" for the patient. The patient's wish of home-based care would never be actualized, if the family of the patient says, "No, we do not have time to take care of the patient."

For home-based care of terminal patients, research of Ishikawa Prefecture suggests that medical staff should mitigate the pain of the patient and then tell to the patient and the family of the patient about the appropriate prognosis and the name of the illness. The staff should confirm the wishes of the patient / the family of the patient about taking care of the patient at the end of life at their home, respect the family of the patient to take care of the patient at the end of life, construct the infrastructure of a home-care system for terminal patients with the cooperation of other related organizations, and give information on grieving to the patient / the family of the patient, even before death happens (Mizushima, Y. et al. 2005: 12). This research addresses the importance of preparation for death through helping family members to adjust to and/or to face death.

However, present-day patients in general are more likely to die in medical settings. Thus, the venue of the final moment for Japanese people is increasingly away from home-based care. That is the reality of Japan with the focus on medical technology as the means of maintaining the quality of life for the patient.

## **7. Research into the role of medical staff in caring for patients at the end of life**

In light of the communication problems between physicians and their patients, and between patients and their families when caring for patients at the end of life, members of the nursing team become important, with the physicians of the patients. In Japan, nurses have begun actively intervening to deal with the psychology of patients, in order to help them cope with their disease driven conditions, regardless of whether they have known and/or have not known their own disease driven diagnosis. The attitudes of nurses matter to help the terminally ill patients keep hope at the end of their life.

The medical staff members of Oita Red Cross Hospital in Oita Prefecture, Kyushu, noticed that both listening to the patient's worries about life and death and trying to exchange views between the patient and the nurse, are very important for helping the patient to be able to think of

how to live right now, and then to discover what is the meaning of life for this day, as well as eventually to help the patient's wish made for his/her life with dignity maintained (Shoji, M. et al. 2005: 20). This article goes beyond the suggestion of "Be a good listener!" as the universal gesture welcomed at any medical interaction.

The medical staff members of Shin Sapporo Kei-ai-kai Hospital in Sapporo suggest that nurses should take a holistic approach to understanding the patient's background as well as trying to figure out what kind of quality of life the patient really wants to maintain (Koyanagi, Y. et al. 2006: 124). This article addresses the relationship between telling truth about cancer to the patient and the patient's search for the value of self-existence during end-of-life.

According to Davis and Konishi, Japanese nurses believe that "the Japanese norm of nondisclosure renders little possibility of informed consent" (Davis, A. and Konishi, E. 2000: 90). Or, nurses have claimed that "Once a physician withholds information or lies to a patient, the nurse cannot correct this situation although the nurse may feel that such actions are unethical and against the patient's wishes" (Konishi, E. and Davis, A. 1999: 185).

Rather than pointing to what physicians said to their patients, Japan should learn from the medical practice of the U.K. and the U.S.A., where the status of nurses has been improving with much stronger responsibilities for and commitment to patients' treatment and care at the end of life. Japanese nurses are anticipated to be educated on patients' treatment and care at the end of life in particular, while pondering the differences of traditional values embedded in patients at the end of life either in Japan or in the West.

The hospitals of no truth-telling practice face conflicts between (a) the patient's wish to know truth and (b) the hospital staff not to tell truth. As one patient said, "Do not hide, but ... tell me ... about what's happening ... Let me know my ... disease!!!" (Yoshida, S. 2000: 150f.). These utterances of the patient are not recommendable for a patient to do a complaint. In order to make the nurses understand what the patient wants to know, this patient should have said differently, with a clear voice and confidence, without any incomplete sentences and emotional utterances. Accordingly, what was shared by the medical staff was the uncertainty of whether these utterances might reveal this patient's honest confession or just a fear. Hospitals in Japan continuously have a gap in understanding between patients and medical staff (Yoshida, S. 2000: 154).

Any dialogue exchanged between patients and medical staff is anticipated to straighten out what patients want, because "effective, culturally sensitive communication is a necessary part of providing high quality care" (Powell, T. 2006: 19).

Because Japanese patients' voices are hardly heard by medical staff, Dr. Kuroyanagi said; "what is needed is "yasashisa" ("compassion") of the physicians and nurses" (Kuroyanagi, Y. 1994.

84 – 85). In reality, however, “Physicians of no “*omoiyari*” (“sympathy”) to the patients and their families have been dealing with the patients” (Kuroyanagi, Y. 1994: 95).

In Niigata Prefecture, the nurse tried out the written note exchanged with the patient of the disease already told. The following questions were asked to the patient: (1) What kind of feelings have you got right after the diagnosis told?; (2) What are your pain and suffering right now?; (3) How do you want to live during the remaining time?; and (4) Are there any other comments added? This can help change the attitude of the nurse, i.e., to cultivate insight into what the patient is feeling, because the assumption of no problem by the patient is expected to prevail, if nothing is said by the patient (Kashiwagi, Y. 2003: 217). “Truth-telling followed by any appropriate medical care of the patient” is a set practice, as Dr. Iwase wrote, “truth-telling itself is no problem. But, the care of the patient, right after truth-telling, is the core problem to deeply think of” (Iwase, S. et al. 2004: 46 (312)f).

In Nagano Prefecture, more than 90% of the patients in one ward of the hospital were told their diseases. In their interactions with the patients of truth already known, nurses focus on the following points: to mitigate the patient’s feelings towards death by telling the nurse’s idea of death; not to hide with words, but to try to accept what is said by the patient; and to communicate with the patient through the nurse’s own words (Terasawa, Y. et al. 2003: 195). This article is valuable as a means for other nurses to reflectively evaluate (a) what they say to their patients and (b) how they help patients to be encouraged and/or empowered, once telling diagnosis has been executed.

Through investigating what patients were aware of concerning their disease, nurses listed their patients’ important utterances, i.e., “for me, the patient, the best thing is with the nurse who can ask the physician about what I really want to ask. When the physician is telling me about the disease, I want the nurse with me. The explanation of the nurse once again, right after the physician’s talk, is really helpful for me” (Nomura, T. et al. 2005: 485). This example reveals the gap between the patient and the physician not only in medical knowledge, but also in communication style. Physicians appear to find it difficult to adjust themselves to the comfort zone of the patients. Japanese physicians’ truth-telling is to be urgently changed to honest interactions with patients, as if they were talking to their parents and/or grandparents.

Japanese nurses are expected to support the emotional needs of patients’ families: “nurses should understand and support the families who bear the burden of not telling the true diagnosis to their loved ones and who are not able to understand the patients’ awareness of the diagnosis” (Mizuno, M. et al. 2002: 396 – 403).

I believe that to understand the real relationship between the patient of no disease told and his/her family is a daunting task for any nurse, as Japanese people are prone not to tell genuine feelings to outsiders of the family to avoid any shame disclosed. Accordingly, this pattern of non-disclosure tends to escalate, particularly in the families of cancer patients. The word “cancer” is avoided by the families for separating patients from their cancer. Tanimura, et al. use the term “shielding”, not only hiding, but protecting the patients from danger and outside threats. Nurses who wish to keep the rights of the patient can ask the family to deeply think of “shielding” with the following question of: “Would “shielding” be good or bad to the patient himself/herself?” For both, the nurse and the family, it is vital to investigate how any better process would be of telling cancer to the patient (Tanimura, C. et al. 2004: 45).

Here, the question would be: What would be the best policy of nurses under such situations of the patient being unaware of his/her own disease? The role of a nurse is “to try to help both, the patient and the family of the patient, share the same information as much as possible” (Hirao, Y. 2004: (289)87f.).

A support group or program organized by a hospital is rarely available in Japan. Thus, the nurses of the hospital have to function like a support group for the patient and the family of the patient who may not have experienced mutual sharing (Yamazaki, T. Heisei 18<sup>th</sup> year, 2006: 97). This lack of infrastructure is rooted in the “family-managed society” of Japan. Thus, any problems within the family are anticipated to be solved within that family, behind the closed doors of the family. Consequently, no one ventures to break the rule of the family, as the unit of Japan, by stepping into the invisible, but always existing psychological boundary separating one family from any other family in Japan, unless the specific reason is officially justified. In Japan, no individual person can be socially visible and identified apart from the family. Japan measures the individual only by membership in the family. Thus, the intervention and the help of nurses, the outsiders, may be the challenge towards the reality, the family of Japan.

I believe, however, that any appropriate staff (for example, a chaplain for spiritual help, a counsellor for psychological back-up, or a social worker for financial problems) should work to genuinely understand and solve the patient’s and the family’s problems in coping with life and death. Thus, I hope that an interdisciplinary team with such professionals could be actualized to lessen the nurses’ current extra over-work and to give maximum support for the patients and their families to scrutinize their specific problems.

In reality, however, I suspect that Japanese patients and their families would prefer not to easily tell their buried questions of end-of-life directly to “outsiders” such as the chaplain, counsellor, and social worker, due primarily to the “shame” attached. Thus, the first step needed is

to let Japanese people know the gap between Japan and the West where such professionals' help is available. I will discuss strategies for facilitating better and more frank exchanges and communication between patients and medical personnel in chapter five.

### **Conclusion to Chapter Four**

This chapter has examined truth-telling and treatment practices in end of life care in Japan. Various research studies and survey data were analysed to show the prevalent tendencies regarding how physicians (and, to a lesser degree, nurses) interact with patients and their families in Japan. Many of the research studies are based on truth-telling in the context of cancer care. The case of one of Dr. Yamazaki's patients illustrates the type of approach to 'shielding' cancer patients from the truth of their disease that is typically applied by family members and physicians in Japan. Some notorious legal suits concerning medical malpractice at the end of life were examined, and various instances of good practice were highlighted. The Japanese guidelines on the treatment of patients at the end of life were summarised. This was followed by a broader discussion concerning home-based care of those at the end of life, and research into the way in which nurses and the wider medical team can play an important role in answering the questions and deepest concerns of patients. These matters will be explored further in the next chapter.

In light of the studies discussed above, it appears that truth-telling has not been fully practised in Japan. This means that Japanese patients have not yet experienced making their own decisions with alternatives of treatment told by their physicians. Patient autonomy can never be exercised without any choices of treatment given. As Ruhnke states: "Views concerning doctor-patient communication about cancer in Japan bear a similarity to views that were prevalent in the United States several decades ago" (Ruhnke, G. et al. 2000: 1178 – 1179). This is because, in Japan, paternalism is still practiced by physicians and tolerated by patients and their families. What justifies such a practice is the strong tradition of the family system. Physicians confide about illness not with the patient but with the patient's family, which acts to undermine patient autonomy.

No change will happen, unless there is a mutual change on the part of both parties: physicians and patients / their families. What is needed is that Japanese physicians change their practices to provide patients and/or their families with full explanations of disease to help patients make their own decisions about their treatment. Japanese physicians are anticipated to ponder (1) how to tell and why to tell the truth of disease and (2) how to tell any bad news included, prior to actual interaction with patients and their families.

On truth-telling vs. its readiness of Japanese patients, patients want to have the family's and physician's support for the truth actually told, because as Elwyn et al state: "many patients in Japan

may wish to confront the truth but lack the courage to do so on their own, especially without the support of family or physician ... The initiative [of disclosure] can, and perhaps should, come from physicians” (Elwyn, T. et al. 2002: 292). Both proactive and passive attitudes of Japanese patients appear in the following study: “a majority of Japanese patients have positive attitudes towards participation in medical decision making if they are fully informed” (Sekimoto, M. et al. 2004: 5:1). Here, the question is: Who is responsible for full information given, except for the physician?

Through reflecting on this discussion, I propose two practices as needed: (1) truth-telling directly from the doctor to the patient and (2) truth-telling directly asked from the patient to the doctor. These practices of telling and asking in which the psychology of both the physician and the patient is deeply embedded, are the bases to make every interaction crystal clear in Japan, because, firstly, truth-telling is to facilitate “patient autonomy” with the patient’s decisions made, and secondly, the patient’s asking questions of the physician should be allowed in order to ascertain the truth of disease.

I believe that asking is the genuine demonstration of what the patient is right now crying out for. Ideally, on the transparency and accountability of the disease of the patient, both, (a) telling truth between patient and physician and (b) their asking questions of each other, are vital virtues as well as strategies for their mutual understanding of the patient’s disease, because truth-telling can never be completed without having the patient’s own input on the disease’s history, fears of other disease, and/or any other particular concerns. Thus, I genuinely wish that both - patient and physician - would become the equal partners of helping each other in order to jointly ponder and shape what is the truth of the patient’s disease in terms of diagnosis, treatment, and prognosis.

Anyone with the patient at the end of life is expected to thoroughly understand the value of the patient, i.e., his/her way of life as a human being, along with the carer’s wishes of how to behave and interact with the patient. Both the patient and the carer can influence each other, face to face, to mutually confirm that they share the life of human beings together (Nishimura, T. et al. 2006: 25f.).

I would hope that the exercise of mutual understanding and respect would genuinely affect the content and quality of the information disclosed to the patient from the doctor. Nishimura’s article is of great help to touch the nerve of the individual’s inner mind to eventually help build up a better human relationship not only in medical practice, but also in any other context, based on mutual understanding and respect between different parties sharing the same humanity.

In short, the mission of medical staff appears in their interaction with patients.

Physicians [in Japan] struggled with their own moral dilemmas in finding the best way to care for patients within the limits imposed by the clock, their careers, and their values (Long, S. 2000: 12).

Patients are invaluable to educate nurses in the clinical settings, as the nurse says,

Patient care is the great responsibility for the life of the patient,  
but, the patient's care is, at the same time, to educate me and  
to develop me as well (Teramoto, M. Showa 60<sup>th</sup> year (1985): 109).

In the next chapter, I discuss the need for more effective communication between the medical team and the patient / his or her family. I consider the two-way interaction between physician and patient, and I propose various means of improving the quality of interaction and/or communication between them.

## **Chapter Five**

### **Developing trust and critical & creative contemplation (“CCC”) for truth-telling medical practice**

#### **Abstract to Chapter Five**

In this chapter, I will discuss how to promote trust and truth-telling by fostering effective communication in the medical setting. I begin by identifying some of the blockages to effective communication in medical settings. I then discuss some ways to overcome these traditional barriers to effective communication, proposing a number of concrete strategies that can be enacted in order to build trust and create effective bridges between medical provider, i.e., doctors or nurses, and medical receiver, i.e., patients with family. I argue that a reflective practice that I have named “Critical and Creative Contemplation” (CCC) can be employed to promote better interaction for communication in medical settings.

#### **1. Identifying the blockages to effective communication in medical settings**

The practice of truth-telling in a medical context relies on effective communication between the physician and the patient, and also between the other relevant individuals such as additional members of the medical team and the patient’s significant others, including next of kin and family members. Truth-telling begins with either the patient or the physician by breaking the silence of the disease driven problem. Ideally, both the patient and the physician should contribute to truth-telling as the joint composers of what truth exists within the patient’s disease. Such an ideal situation, however, may seldom arise in real clinical settings.

Communication between human interlocutors in a medical context can be difficult for many reasons. Various factors can make effective communication difficult, so that the necessary flow of information about the truth of a disease (in terms of its diagnosis, treatment, and prognosis) does not occur as well as it should. These barriers to effective communication may be due to personal factors, cultural factors, or institutional factors (such as insufficient time for a proper exchange between the patient and the physician). The various factors affecting the quality of communication and information exchange, and the practice of truth-telling in relation to diagnosis, treatment, and prognosis of the patient at the end of life are discussed in more detail below.

#### **1.1 Barriers to effective communication in the physician-patient relationship**

For patients at the end of life, especially, where one has to communicate about matters of grave illness and imminent death, it may be difficult for patients and their physicians to confront and



communicate the truth about disease. In the patient-physician relationship, before there is any spoken exchange between them, there can be other discourses deeply interwoven in any interaction between patient and physician, such as any power struggle between patient and physician; a gap in medical knowledge between them; and a gap between the patient's direct experience of disease and the physician's indirect experience of disease. These elements that affect the nature of their interaction may have their roots in differences in philosophical, ethical, psychological, social, and spiritual outlooks, or in the different personal experience and/or backgrounds between patient and physician. Thus, all of them can set up an opposition between the patient's thinking and the physician's thinking. Consideration should include: (1) any other tangible and intangible factors which might hinder interaction between them; (2) any other visible and invisible elements which might change the flow of interaction between them; (3) any other reasons which might trigger a power shift between them; and (4) the patient's real worries about how he/she can articulately express what is needed to the physician with the appropriate language & body language to maximise the limited time of their interaction in order to solve problems. The employment of different repertoires in the discussion of problems, depending on the individual style of getting the message across, also affects relationship dynamics.

Even when the same language is used between physician and patient, there may be intra-cultural differences based on the personality of the individual that may hinder and/or help develop interaction of truth-telling. I sadly swallow that language is merely a tip of the iceberg in which the different value systems of both society and each individual person are embedded. The relationship of trust between two parties – patient and/or family and physician – can only be established on the basis of some common ground or shared values. This will in some respects reflect the society in which the both parties live under so called “common sense” or a similar value system usually shared. That is to say, the interaction of truth-telling of the patient's disease represents the psychosocio-cultural-religious dimensions of the society itself.

Pertaining to the relationship between (a) the characteristics of society as directly and/or indirectly influencing approaches to truth-telling (the concept and its practice) and (b) the practice of informed consent at medical setting, as I mentioned earlier in this thesis, the Japan Medical Association (“Nihon Ishikai”) finally admitted that Japan needs to have its own Japanese version of informed consent, due to the reality that Japan is different from the West in terms of the nature of society.

Just like the Bible states to appreciate a variety of languages spoken among human beings, the diversity of languages, cultures, and/or religions is a part of everyone's daily life here in the UK and/or the USA. Thus, the conscientious British and American physicians with whom I met and

directly heard their voices have already begun to learn world-wide religions to understand their new patients and/or families born in other countries in terms of their different value systems compared with local patients, because making decision of treatment of disease is connected to their value systems, even though they are in fact expected to understand the medical practice of the UK and/or the USA. With the consideration of a new and fluid nature of current global village with many different nationality driven persons living together as neighbours, I propose Japan should reconsider / re-visit her current medical climate of trust rooted in the hierarchical society rather than simply accepting that Japan is different from the West as the justification of the Japan Medical Association (“Nihon Ishikai”). This is because we are in the 21<sup>st</sup> century and even Japan is a part of a global medical community and world-wide humanity. I believe that the era of the Japanese only importing medical knowledge and experience of the West has gone and is now replaced by a relationship of exchange, based on the mutual collaboration between Japan and the West. Then, I wonder if the boundary of two concepts between similarity and difference would get blurred and eventually to force us all to re-check these meanings and our assumptions about them with the questions: What is the basis to separate between difference and similarity? Why? What do we share in common, and how can we learn from one another’s difference?

Here, I would stress that the individual person, irrespective of patient and/or family and physician and/or medical team, is consciously and/or unconsciously to input his or her own interpretation into the societal values in which he or she resides, while acting out his or her own interaction over the patient’s disease connected either to begin to create trust or to begin to end trust at any moment.

## **1.2 The historical emergence of the value of truth-telling**

Historical factors have prevented effective communication between physician and patient. As this thesis has demonstrated, over the course of the twentieth century, there was a developing awareness of the importance of truth-telling as a value and as virtuous practice in medicine. While truth-telling is today taken for granted as best practice in terms of medical ethics, for much of medical history this was not the case. Recognition of the importance of truth-telling in medical practice has developed hand-in-hand with the growing recognition of the importance of disclosure of information to patients, and with the move away from medical paternalism towards patient self-determination and autonomy. As we have seen, within this thesis, in the past, doctors were reluctant to tell about cancer, or of treatments not working well, and/or of likely life expectancy in order to avoid giving: (a) false hope and (b) bad news to their patients. These are understandable

concerns, but today such tendencies are rightly challenged by the patient who wants to know the truth of his/her own disease.

### **1.3 Medical paternalism**

Best practice is firmly established in the replacement of medical paternalism and social hierarchies between doctors and patients with “patient-centered medical practice”, which aims to treat the patient as a whole human being within a more egalitarian social context. Yet, medical paternalism has been and remains a barrier to effective communication between physician and patient.

Paternalistic physicians may simply decide what is best for their patient rather than discuss the disease and any treatment options with the patient. The physician may prefer not to enter into conversation about treatment options with patients and/or next of kin, and discourage discussion about such matters. Likewise, unless the patient succinctly tells his/her physician about his or her concerns or wishes concerning the disease and its treatment, medical paternalism with the physician’s discretion always returns to fill the vacuum when the patient’s voice is absent.

Has the concept of avoiding harm to the patient been replaced by telling truth to the patient? No! The goal of avoiding harm is powerfully embedded in each patient’s treatment, prior to any truth being told to the patient. This goal of nonmaleficence still determines many of the decisions made by physicians about withholding information and truth-telling. The qualitative and quantitative nature of harm to the individual patient should always be scrutinised while applying medical ethics, because the patient’s harm is not static, but always fluid and it may surface unexpectedly. It would be ideal to directly ask the patient what range of harm they may be experiencing and whether the harm or hurt is in any way intolerable, as it is terribly difficult to objectively check what kind of harm the patient is experiencing at a particular moment.

In some countries, the move away from paternalism to patient autonomy has been successfully implemented into medical culture and practice. In other countries, traditional and/or cultural practices may act as barriers to patient self-determination and, as a result, the relationship of trust between physician and patient may suffer, along with the quality of interaction and communication between them. In Japan, for example, a continuing climate of medical paternalism customarily prevents the patient and/or family of the patient proposing alternative treatment possibilities.

### **1.4 How best to respect human dignity and difference?**

Patient autonomy and self-determination are embedded in the concept of respect for the dignity of human persons. Indeed, respect for patient autonomy and respect for each patient’s wish are

barometers actually telling that the society has successfully made such a transition to one that promotes human dignity and self-determination.

In reality, human beings are unique and adopt different approaches to many issues, including decision-making at the end of life. We do not know about the value system and personal character embedded in the patient, physician, and/or any individual person. Thus, to acknowledge the difference of every individual patient means: (a) to invite different understandings and interpretations concerning the truth of diagnosis, treatment, and prognosis of the patient and (b) to accept that patients will have different approaches and responses to illness (including issues of diagnosis, treatment, and prognosis) and to death and dying. Respecting the patient's wishes normally involves full disclosure of information to the patient and divulging the truth about their illness. The situation is more complicated when the patient prefers not to confront the reality of his or her medical condition. A further difficulty arises when family members may want to 'protect' their loved ones from knowing the truth.

Unless the patient's real needs are met, human rights remain only as written documents. In order to narrow the gap between (1) any abstract terms of principles and (2) the applications of such abstract terms for truth-telling in the specific medical contexts, people, not only in the West, but also in the East, are expected to ponder what medical ethics is and how it should be used for whether or not a patients' disease is told at the end of life.

### **1.5 Human frailty: denial and avoidance strategies**

We human beings are subjective creatures. Thus, one's enemy is often oneself, because the human being tends to avoid facing the facts about his/her medical condition and avoid openly discussing such things, which makes effective communication difficult. Regardless of whether we live in the West or the East, everyone prefers to avoid discussion about their own death and dying. It is deadly difficult for all concerned, including patients, families, physicians, and medical staff members. I believe that no one can disagree that death and dying are important for every one of us. Thus, when we feel comfortable in ourselves about death and dying, that is the opportunity for us to discuss these matters with any others.

### **1.6 The influence of cultural values and traditions**

In Japan, there is strong respect for cultural values and traditions. Japanese society is ordered according to a strongly hierarchical structure in which social and professional roles carry certain expectations of behaviour, expertise, and responsibility. Social behaviour and practices are

regulated and formalised through strict rules of etiquette. In this cultural model, paternalism is embedded in professional roles, including within medicine, and also within family structures. In Japan these strong cultural influences work against effective communication between doctor and patient and/or family. This can disempower patients compared with doctors, who carry the authority to act out truth-telling. Regarding social interaction, Japan is highly formal based on long-standing traditions and conventions. Eye contact is minimised; speech is controlled – particularly at the first meeting, prior to figuring out who is the interlocutor and what kind of social status the interlocutor has. Questions of “Why?”, in particular, are not often asked. This means patients tend to take what their doctors say on trust. They do not ask questions of their doctors, because this could be construed as a sign of distrust and disrespect. In Japan, the encounter between physician and patient is not a meeting of equals. It is a meeting between an authority figure and the respectful and obedient patient.

## **2. Overcoming traditional barriers and building bridges to effective communication**

These various factors discussed above have inevitably created challenges for how to handle the encounters between physicians and their patients, and how to communicate when there is difficult news about diagnosis, treatment, and prognosis. In this section I propose some strategies for tackling these various barriers and blockages. The patient, family, significant other, physician, medical team, and/or any other individual person related to the patient at the end of life has a responsibility to foster effective communication and to aim for transparency in the free flow of information from physician to patient, and from patient to physician. In this respect, the next of kin and family should endeavour to be a bridge rather than a blockage to that flow.

Members of the medical team must interact with patients and their family in such a way that they foster an atmosphere of trust – a trust that must be built up in every encounter in the medical setting. Team members must help to create a climate where the patient can speak aloud their deepest fears, concerns, and questions. The medical team needs to be aware of the art of effective interaction and communication that is required around medical settings at any given time. They must cultivate the skills of listening to and understanding of the utterances of patients, and of “reading the patient’s body language” to pick up any unspoken signs and signals of his or her state of mind and to spot if there might be some unasked questions of the patient. An awareness is required, on the part of the whole medical team, of the psychological, social, cultural, and religious dimensions that may shape the world-view and approach to illness and death of the patient and of his or her next of kin, family.

All the interlocutors must be attentive to: (a) any cues, i.e., eye contact, of either stopping / causing an impasse or developing the flow of utterances between the interlocutors; (b) any positive or negative vocabularies or medical jargon as the ramifications of the contents at the end of life related to truth-telling of diagnosis, treatment, and prognosis; (c) any language and body language as the repertoires of how to present and/or identify who he and/or she is as the individual interlocutor; (d) any other signal based on the psycho-socio-cultural-religious aspects of truth-telling of diagnosis, treatment, and prognosis at the end of life in the specific context; and (e) any other tangible and intangible factors to be observed and/or not to be observed depending on who the individual interlocutor is as patient, family, significant other, physician, medical staff member and/or any other person connected to the patient at the end of life.

Every individual person should adopt a positive and open minded attitude towards truth-telling: the concept and its practice in his/her own daily life, such as, (a) to be attentive to the latest world-wide news on truth-telling of diagnosis, treatment, and prognosis at the end of life; (b) to be interested in the patients of the latest world-wide news as our fellow human beings, not as the mere subjects of diseases. And also to put ourselves into the patients' situations and think of their problems; (c) if our family member happens to become terminally ill patient, we should genuinely help the loved one; (d) if possible, we should visit the sick and seek to genuinely understand patients at the end of life; and (e) as the extension of our current target: of treating the patient as a whole human being, new strategies to support effective communication and truth-telling should be created and acted out in order to change not only medical culture, but also ordinary people's attitudes towards patients at the end of life.

## **2.1 Trust in the service of truth-telling (the concept and its practice)**

A Medline search of journal articles with the combination of the keywords of trust, telling the truth, and end-of-life related treatment displays only one article in German with its abstract in English as shown below:

The ability to guide serious sick patients and to help in terminal cases depends on the helper's personal attitude to death and questions of eschatology. The concept of truth means not only correct information about findings of examinations but rather a veracious relationship based on mutual trust between patient and doctor. All co-workers especially the nurses participate in the process of helping the patient. There is no model program for the talk with seriously sick patients nor for the inter-action with the patient. Each situation of terminal cases is absolutely singular and unique. All our behaviour towards our patients is influenced by personal experiences (Zockler, C. 1989: 502).

The article correctly identifies truth-telling as more than mere disclosure of information about the patient's condition. It concerns helping the person to understand the wider reality of their situation and condition. Furthermore, it locates truth-telling within the context of a trusting relationship between communicating persons. The relevant persons involved are not only the doctor and the patient, but also other co-workers involved in care of the patient, including the nurses. One could also add healthcare chaplains to this group of co-workers.

Zockler's article makes no mention of the duty of veracity towards the patient's family and friends, who may also be involved in the patient's end of life care and therefore in close contact with the medical team. One can see that there is a complex set of people involved in the end of life care of the patient and we need to consider the role of trust and truth-telling in the relationship between all these stakeholders. At the centre is the patient who must reflect on the central questions that arise at the end of life, such as questions of one's own mortality.

I wish to argue that trust is an essential ingredient in the physician-patient relationship if effective communication and problem solving concerning the patient's treatment options are to be explored. At the same time, effective communication is necessary in order to build trust between the interlocutors in the medical setting. Trust is, therefore, both a prerequisite and a product of effective communication.

Trust between persons is built through interacting: both by verbal and non-verbal expressions, i.e., utterances, silence, facial changes, eye contact, other body language, and any other cues picked up by the interlocutor(s) about whether or not to engage in a trust relationship. The process to reach a trusting relationship is a learning experience for both parties, while they are trying to ascertain the different values of the interlocutors with mutual respect. Trust is strongly created only when both parties can accept the dignity of the other individual person, as in Kant's term of treating the other person always as an end. The trustworthiness of individuals goes hand-in-hand with the trustworthiness of society. Thus, the more individuals try to become trust-conscious human beings in their everyday life, the more society becomes a trust-conscious entity with ethical rules diffused at both personal and societal levels.

Trust or trustworthiness is the keystone of medical virtue, from the Hippocratic Oath to the American Medical Association (AMA) codes of medical ethics. Trust is the basis of professional ethics (Dyer, A. 1985: 230f.). According to Kenneth Calman, this entails:

truth, openness, and sharing; respect for the views of others and tolerance; the rights of others to make decisions and autonomy; doing your best for others, not doing harm; keeping promises; sharing difficult times together. ... If trust has been established, then the problems that arise will be easier to deal with (Calman, K. 2002: 168).

Honest information disclosure and telling the truth are intimately related to the building and nurturing of trust between physician and patient. As Hebert states: “The candid disclosure and discussion of information not only helps patients to understand and deal with what is happening to them but also fosters and helps to maintain trust” (Hebert, P. et al. 1997: 226). Thus, mutual honesty is a reflection of the trust between the patient and the physician. Mutual trust between the patient and the doctor is the ideal situation that should be fostered. Withholding information or deception can fatally undermine trust and lead to a collapse in the doctor-patient relationship. Trust is difficult to build up, but very easily lost. As Calman states, “Trust come on foot and goes on horseback” (Calman, K. 2002: 168).

In the context of the modern hospital, there is often insufficient time to genuinely foster a trusting relationship. Today, along with the pressures on medical staff, all doctors do not take enough time to genuinely treat the patient as the end, to use Kant’s term. Instead, where the relationship between the patient and the physician is at stake, the patient has no other choice, but blindly to trust in whatever the physician has told him or her. This is even more the case in paternalistic medical settings, where trust is based upon the patient’s unquestioning acceptance of what the doctor advises.

The anatomy of trust is discussed by Annette Baier. According to Baier, in normal human interactions, the other person to be trusted is supposed to ascertain what would be the expectation of the truster by “picking up the cues that indicate the limits of what is entrusted” (Baier, A. 1994: 101f.). Such consideration of the other person trusted would be called a discretionary responsibility, or discretionary power to allow the person trusted to make a judgement about what the truster wants.

The more extensive the discretionary powers of the trusted, the less clear-cut will be the answer to the question of when trust is disappointed. The truster, who always needs good judgement to know whom to trust and how much discretion to give, will also have some scope for discretion in judging what should count as failing to meet trust, either through incompetence, negligence, or ill will (Baier, A. 1994: 103f.).

The patient can become the victim of the physician’s discretionary power, when the physician behaves paternalistically. Just like a child under the parents’ control, the patient can fall under the control of the physician. However, a different form of trust can flourish in settings where patient autonomy is respected and promoted. The concept of trust changes depending on the quality of both: (a) the patient’s involvement in the dialogue process and (b) the physician’s responsibility and mission acted out in daily interaction with the patient.



The trust relationship with each patient can never be created just overnight. The time or timing is deadly crucial whether either patient or physician would begin to trust. And mutual trust would come or not come to eventually maintain or not to maintain trust relationship over the patient's disease to be solved.

When and how trust is felt to be established may differ between cultures. Or, the litmus test of how much trust relationship is created is in the consciousness of the patient or the physician who is directly and/or indirectly exposed to the value system of the society. When I was with American patients at the end of life stages either in hospitals or in nursing homes, they were more open, honest, and genuine to tell their own problems to me right at the beginning of the interactions, whereas Japanese patients at the end of life would hardly tell anything to me, the interlocutor. Their first response is to try to figure out who the interlocutor is by just observing. Thus, I feel that a much longer time is needed to feel trust between interlocutors in Japan compared with the time invested in the USA and the UK.

Likewise, generally speaking, in Japan a great deal of time is invested to check on and test the trust between persons, and to determine whether to begin, develop, and maintain trust with any other Japanese person in any context of Japan. Palliative treatment is a venue where a great deal of trust is required, prior to the actual treatment of the patient, because the quality of life and holistic wellbeing of the patient are both equally essential, and the feeling of the patient towards the medical team is deadly important, as it can never be separated from how much trust the patient actually has obtained.

Sympathy and empathy are related to trust in the patient-physician relationship, for both are needed for physicians to fully understand and care about the pain and worries of the patients. Although customarily any comment is hardly ever spoken by ordinary or grassroots Japanese people with clear words, the sympathy and empathy of physicians and other medical staff are taken for granted in Japan. In comparison with sympathy and empathy, compassion is the general term to care, for example, Jesus is compassionate. In terms of the relationship between subject and object, we are, however, prone to exercise the transfer of our own feeling to all objects, i.e., the interlocutor or anything around us with the following two steps taken: at first, we are to input our own feeling to everything around us and secondly, we are to believe that the feeling of ourselves originally existed within the object of the interlocutor and/or anything around us. (Shimazaki, T. the 27<sup>th</sup> year of Showa (1952): 118f.). Kuroyanagi M.D. expressed his terribly sad feeling about other Japanese physicians' lack of sympathy. (Kuroyanagi, Y. 1994).

In the similar milieu, regarding what should be the sympathetic manner of physicians, a Japanese female medical doctor said to me, "I've not thought of such expression, sympathetic

doctor” in a meeting in Tokyo, Japan, in 2009. This shows the huge gap between the individual Japanese patient and the medical staff regarding what sympathy really means in our contemporary Japan.

## **2.2 Glaser and Strauss’s USA-based research findings of the 1960s**

Trust is embedded as a pre-requisite in the patient-physician relationship, and intertwined with how truth-telling is executed from physician to patient. Trust shapes how full and frank the patient is about his or her medical symptoms with the physician. Trust is built through effective communication and, in turn, trust makes effective communication easier and therefore helps promote truth-telling. These themes are explored through an analysis of American research entitled “Would patients die socially before they die biologically?”, which examines real patients’ feedback towards their physicians’ utterances. These show how patient-physician interaction influences patients’ physical health and mental wellbeing at hospitals.

In the mid-1960s, Barney Glaser and Anselm Strauss conducted their research of intensive fieldwork at six hospitals of San Francisco specifically situated in the Bay area, USA, with the question of: “Would patients die socially before they die biologically?” to obtain knowledge of how the dying processes of the patients were handled in the hospital settings. Thus, I below picked up seven scenarios in which trust is either threatened or established in the end-of-life setting, since the investigation of the processes of interaction between the physician / other medical staff and the patient at the end of life is terribly needed, because as the researchers state, “everyone is a different personality, so dies differently and must be handled differently” (Glaser, B. and Strauss, A. 1966: ix).

This study reveals good practice in relation to dealing appropriately with dying patients, but also reflects a number of paternalistic assumptions prevalent in the U.S. during that era, including withholding information from the patient.

### *1) Trust cannot be created overnight.*

The importance of keeping trust can be seen in the dilemma of an unaware patient who has long placed trust in a particular physician, but whose suspicions have now been aroused by some incident or remark. Can the man still be trusted in this new domain, trusted not only to “pull me through my illness” but “to tell me the worst”? In general, the physician and others must not arouse any suspicion by their words and actions that they are concealing knowledge about terminality (Glaser, B. and Strauss, A. 1966: 34).

2) *The truth of the patient's disease can never be camouflaged.*

The true situation can be deliberately conveyed to a patient by facial expression, by carefully oblique phrasing of words, or merely by failure to reassure him about his symptoms and prognosis. And of course the family members may occasionally signal or hint at the dreadful truth. Indeed, when the family actually knows the truth, the hazards to maintaining closed awareness probably are much increased, if only because kin are more strongly tempted to signal the truth (Glaser, B. and Strauss, A. 1966: 42).

3) *Nurses may need more strategies to maintain trust with the patient.*

The nurses customarily share some of their observations about the suspicious patient, so that all can present more or less the same line to him. Nurses generally need to develop both common and personal tactics more than the physicians do, because they spend more time with the patient and are more likely to be asked extensive indirect queries. (Some patients, perhaps especially those of lower socioeconomic status, do not like to approach their physicians too directly, out of consideration for their high status) (Glaser, B. and Strauss, A. 1966: 57).

I think that the above tendency of the nurses to become targeted by the patients concerning whether or not the truth has already been told by their physicians is seemingly the same as that of Japan. Numerous Japanese patients do not want to directly ask their physicians, because of the vertical society of Japan.

4) *Trust goes with candid interaction between the patient and the physician.*

One doctor walks into the patient's room, faces him, says, "It's malignant," and walks out. To be sure, this tactic also eliminates having to answer the patient's questions ... Another form of sharp announcement is the *direct retort*: when a patient asks, "Doctor, do I have cancer?" the doctor replies, "Yes, you do" (One doctor commented, "If they ask directly, we answer as directly as possible") (Glaser, B. and Strauss, A. 1966: 125).

Neither of the approaches outlined here is acceptable. I believe that the "eye-to-eye" contact at interaction must be made in the specific context where the patient is desperate to know the truth of his/her disease.

5) *Trust in the context of tacit acknowledgement of terminal illness.*

This doctor continually maintains a cheerful and optimistic manner, never directly disclosing to the patient that he will die, but actually giving *silent disclosure* by his offer of comfort surgery or participation in a clinical experiment. Silent disclosure initiates the mutual pretense awareness

context: both doctor and patient know of the latter's fatal illness, and both know the other knows, but they do not talk to each other about it (Glaser, B. and Strauss, A. 1966: 125).

Mutual avoidance of confronting the issue can create an "Elephant in the room", or a kind of mind game between doctor and patient. Silence can also lead to uncertainty about the illness, rather than tacit acknowledgement. The above mentioned situation is the most difficult one between body language and language itself, as the trust between the different parties is subject to the interpretation.

#### *6) Physicians' attitudes change the trust of the dying patients*

As one doctor put it, "If you know it is necessarily ultimately fatal, then you may not work too hard." The increasing absence of a doctor who has previously been more attentive can make an unaware patient suspect that he has been given up for lost, since he obviously isn't getting better. Thus, this basic structural feature of medical practice --- the high priority assigned to patients who can recover --- linked with the "nothing more to do phase" may endanger a closed awareness context, for most people know that doctors disappear only when either recovery or death is certain. The patient's suspicion can easily change to open awareness, if the doctor cannot adequately counter the accusations of neglect and incompetence (one patient yelled: "You're no longer a doctor") leveled by a suspicious patient when the doctor makes one of his brief, infrequent visits (Glaser, B. and Strauss, A. 1966: 181).

This disclosure by neglect is unacceptable. The patient deserves an explicit diagnosis. Ideally speaking, the physician should sit by the bedside of the patient, while keeping the same eye level as the patient's eye. This moment of such body language, sitting with eye sights' level met between the patient and the physician, is vital to genuinely being present to enable authentic interaction between doctor and patient.

#### *7) "Role switching" of staff members to help dying patients understand disease and death*

One nurse reported, "I can talk to patients about death. In fact, nurses call me in to talk to patients because I am able to do this." In a Catholic hospital, three of the older nuns, retired as nurses, were on call for talking with patients about death and dying. Chaplains, social workers, and psychiatrists are sometimes able to take over this task. In these instances the nurse employs the "role switching" strategy to maintain composure (Glaser, B. and Strauss, A. 1966: 243).

Patients' problems and worries are limitless between purely medical and non-medical concerns. Thus, a variety of professionals are needed for either listening to the patient's talk quietly

or discussing viewpoints between the patient and the medical staff. Then, by breaking through the patient's dead-end problems, both parties would hopefully manage to share the meaning of life followed by peace of mind in the midst of the dark tunnel, right before end-of-life driven moments.

Along with the similar vein of how to help patients feel they are cared for, a fraternal relationship between doctor and patient should be envisaged as very valuable to be actualized, as Berger and Mohr mention below:

When I speak of a fraternal relationship or rather of the patient's deep, unformulated expectation of fraternity I do not of course mean that the doctor can or should behave like an actual brother. What is required of him is that he should recognize his patient with the certainty of an ideal brother (Berger, J. and Mohr, J. 1967: 63f.).

Regarding Physicians' hospitalization, I believe that the first-hand experience in hospital as a patient would be of great help for anyone to become the physician of sympathy and empathy. An American physician once quipped: "one might suggest, of course, that only those who have been hospitalized during their adolescent or adult years be admitted to medical school" (Ingelfinger, F. 1980: 1511). To extend further in the similar milieu, a good doctor would be, as if he /she were the patient, as stated below:

How is it that Sassall is acknowledged as a good doctor? ... Sassall 'becomes' each patient in order to 'improve' that patient. He 'becomes' the patient by offering him his own example back. He 'improves' him by curing or at least alleviating his suffering (Berger, J. and Mohr, J. 1967: 63f.).

I believe that the physician, with the attribute and behaviour stated above, is par excellence or the great example of how the physician should be.

### **3. Critical and Creative Contemplation ("CCC"): A proposal to develop insight and interaction between (1) patient and/or family and (2) physician and/or medical team**

Note. The family stated above within "(1) patient and/or family" means family members as "family caregivers" who take care of their loved one – the patient – during his or her stages at the end of life.

In light of the observations I have made concerning the blockages to effective communication that can exist in the medical setting, and how to overcome them, including the necessity for trust to be established between the providers and recipients of medical care, I would like to recommend an approach that I will call “Critical and Creative Contemplation” (CCC). CCC is a practical means for helping both parties: patient and/or family and physician and/or medical team – that is to say, the recipients and providers of medical care – in terms of creating and developing a thorough interaction on truth-telling for the patient at the end of life.

CCC is an attempt to improve communication – in this case, between those involved in the end of life care. It is an effort to make communication clearer and more authentic. CCC can be used within the process of making decisions at the end of life in order to check what is important to think, ask, and ascertain between patient and/or family and physician and/or every individual person related to the patient’s final care. Critical and creative contemplation is therefore a praxis (a form of reflective practice) which assists an interaction driven individual person to enact an effective communication over the problems of the patient’s death and/or dying stages. It is anticipated that CCC would facilitate truth-telling actualized and suited for the patient’s preferences and decision-making, together with the family’s collaboration to best meet the needs and desires of patients around the unforgettable time of the patient’s care at the end of life.

Before elaborating how CCC would operate in practice, it is necessary to draw attention to the importance of critical thinking in medicine. The questions of what, how, and why were addressed as important in the dialogue and/or debate between Socrates and Meno through the filter of Plato on the Socratic method of interaction between interlocutors. The history of philosophy is the actualization of different views exchanged between interlocutors through what, how, and why driven questions in order to narrow down and ascertain the gap between experiences of human beings in terms of theories to be framed, hypotheses to be created, evidence to be judged, truth to be ascertained, and falsehood to be pointed out. In order to address the importance of critical and creative thinking and questions of what, how, and why, I will introduce the following two articles.

First, in 1991, Daniel A. Moros, Department of Neurology, Mount Sinai Medical School, New York, N.Y., USA; Rosamond Rhodes, Department of Philosophy, Hunter College, City University of New York, N.Y., USA; and others suggested the importance of thinking critically in medicine and its ethics. Among many suggestions, the key advices are (1) thinking critically using data and reasoning; (2) recognizing contradictory statements and/or unanticipated results as a signal to re-evaluate and think critically anew; and (3) ability to evaluate and choose between claims with the possibility of rejecting the alternatives (Moros, D., Rhodes, R. et al., 1991: 245 – 259).

Second, in 2005, John Travaline, M.D., Associate Professor of Medicine, Temple University Hospital in Philadelphia, USA; Robert Ruchinskas, PsyD.; and Dr. Gilbert D'Alonzo, the American Osteopathic Association's editor in chief suggested the questions of why and how as essential for patient-physician communication, because:

the patient-physician encounter involves a two-way exchange of nonverbal information. Patients' facial expressions are often good indicators of sadness, worry, or anxiety. The physician who responds with appropriate concern to these nonverbal cues will likely impact the patient's illness to a greater degree than the physician wanting to strictly convey factual information. At the very least, the attentive physician will have a more satisfied patient (Travaline, J. et al., 2005: 16).

Their further advice is directed to the physician advising him and/or her to anticipate delayed or unexpected responses:

the patient-physician dialogue is not finished after discussing the diagnosis, tests, and treatments. For the patient, this is just a beginning; the news is sinking in. The physician should anticipate a shift in the patient's sense of self, which should be handled as an important part of the encounter --- not as an unpleasant plot twist to a physician's preferred story line (Travaline, J. et al., 2005: 17).

Here, I would argue truth-telling is connected to numerous avenues of medical knowledge, medical experience, and the personality of the individual physician, along with his and/or her own life experience directly and/or indirectly to reveal during any interaction with the patient. Given the fact no ethical principles can provide us with the rescue package to tackle the real problems, we all need to ponder how to apply ethical principles to solve our actual problems. Any interaction with any person in communication in our daily life is the venue to learn from and/or to adjust oneself to any other interlocutors. Every interaction is an opportunity to learn something new, and to benefit from the insights of the other person. Thus, every patient, each physician, and any staff member of medical team can do "practical ethics" by trying out virtues and/or principles of ethics. This is the basis of my proposal concerning critical and creative contemplation.

CCC should be regarded as a means of Socratic self-examination and reflection in order to objectively scrutinize the subjective thinking of any person relating to the patient at the end of life, i.e., patient, family member, physician, nurse, chaplain, psychologist, social worker, and any other staff of the interdisciplinary team involved in the patient's care who has to address questions about the options and/or alternatives to be investigated, about how to solve buried questions, problems, and dilemmas of patient in the critical moments. CCC is a method that when followed can assist

all those involved to adopt the appropriate approach to coming to terms with the illness and treatment programme through truthful and trusting communication.

Creative and critical contemplation can be used:

- First, before any interaction in a meeting between persons, i.e., between patient and any other person, i.e., physician or family member, each person individually to think inwardly of various problems, how to deal with them, and the reasons of why to begin to solve them as the preparation of the interaction.
- Second, after the interaction between the persons, i.e., patient and any interlocutor, to evaluate individually what should have been said, what should have been asked, and/or what are still unresolved problems as the result of the interaction and
- Third, holding a big meeting at an appropriate time in the near future, with the presence of the family member of the patient and the staff of interdisciplinary team taking care of the patient at the end of life, i.e., physician, nurse, chaplain, psychologist, social worker, and/or any other staff of interdisciplinary team, to share and discuss ideas and then to ascertain who is expected to do what kind of work to help solve the patient's problems at the end of life in terms of "responsibility & transparency" actually maintained for the patient's final staged care.
- Fourth, every person is expected to think how to raise awareness among the general public, ordinary people, towards the importance of truth-telling medical practice which can never be separated from the quality of daily life of the patient.
- Fifth, every person is expected to think how to initiate and then develop the change of medical culture on telling truth to patient in order to actualize genuinely "patient-centered medical practice" with the consideration of: (1) patient autonomy, (2) patient's decisions highly respected followed by the execution of the patient's decisions at the end of life together with the help of both: the family members and the staff of interdisciplinary team of the patient's final care, and (3) the patient treated as a whole human being.

CCC is a vital strategy for any person about any problems of relationship at any context in order to learn the lesson from one's own best and/or worst experiences for the preparation of any relational problems to come up in the future. Thus, at the first and the last opportunity when facing death, each person would identify who he/she is through his/her honest decision made based on CCC.



### **3.1 Applying CCC to the providers and recipients of medical care**

How does CCC help mould the role of any person related to patient at the end of life? Here, let me reiterate the strategy of CCC is helpful not only for patient and physician, but also for the family of the patient, the nurse, the chaplain, and any other persons involved in patient care, as pointed out below. Thus, let's begin with the responsibility of the patient – the core person of any medical care – which is the other side of the same coin called “patient autonomy” and/or “patient’s making decision”.

#### **3.1.1 CCC applied to the patient at the end of life**

CCC promotes thorough thinking and reflection by the patient at the end of life in order to differentiate every facet of problems, good and/or bad. The responsibilities of the physician and/or interdisciplinary team of the patient are to treat the patient as a whole with consideration of the patient’s autonomy, making his/her own decision, the quality of patient’s daily life, patient-centered medical treatment, and/or any other critical issues depending on the individual patient. However, as long as the concept and/or its practice of treating the patient as a whole are based on the physician and/or interdisciplinary team of the patient, the voice of the patient is not included. To make the voice of the patient heard, the patient himself and/or herself has to take his/her own responsibility. This means, for instance, that patients are expected to become aware of the needs of knowledge of his/her own disease through public education as well as patient’s own voluntarily taking initiatives with his/her motivation. Otherwise, genuine truth-telling based on the equal contribution of patient and physician to the patient’s disease can never be actualized in real medical situations.

The patient needs to talk to his and/or her own inner self by asking questions such as those outlined below. Here, I must stress that the nature of question would vary depending on the patient, because the individual patient is absolutely individual at least regarding personality, disease, and/or context where he and/or she is treated. The self-reflective questions listed below are therefore indicative illustrations of the kind of introspection and self-examination that might be employed.

- Can I unpack my own disease in order to comprehend objectively as well as subjectively the following concepts: the responsibility of patient, patient autonomy, patient’s decision-making, quality of life, the quality of my own daily life at the end of life, informed consent, respecting patient as a human being, confidentiality between patient and physician, patient centered medical practice, philosophy and ethics of medicine, and any other currently

available concepts related to patient's care at the end of life? If not, can I educate myself of them by reading books and/or visiting websites in the internet? Try to apply such concepts for my own medical situation, i.e., about considering or judging treatment & any alternative treatment in the past, present, and future, and any other problems related to my disease. Think of why I should learn these concepts.

- Every day, can I evaluate my own physical health and mental health objectively as well as subjectively? If I do not have such ability, think of how to check myself objectively in terms of my well-being of each day. And ask myself: Why should I focus on these issues? Who could help me analyse my own health condition objectively as well as subjectively?
- What are my habits enjoyed every day in my life which might have caused me to become the patient of the disease? Think of how to stop, i.e., smoking and drinking alcohol too much without doing diet and/or exercises. Then think of why I should stop them.
- Have I heard from my parents about my family based genetic problems expected passed on from generation to generation? Would the information of the specific gene within my family be of help to make me understand why I have become the patient of the disease? Should I ask my parents and other relatives about any other genetic problems within my family? Why Not? Have I told the physician on my family based genetic problems? If not, think of how to tell the physician as the confidentiality of my genetic problems is duly kept between us. What are my responsibilities to tell my children about any inherited genetic conditions or predispositions?
- Regarding my present disease, what is the truth of disease from my viewpoint? Can I say with confidence that my viewpoint is the right answer to the question of what is the truth of my disease? If I have no confidence, try to visit websites in the internet to obtain information as my home work as soon as possible.
- What is the truth of disease from my doctor's viewpoint? How does the truth of disease differ between my physician and me in terms of diagnosis, treatment, and prognosis? And why does this happen?
- In order to ascertain what is the truth of my disease, should I obtain the second opinion of any other physician? How can I begin with that? Why? Should I tell about such concern of mine to my family and/or my close friend? Why?
- What is the reason for my concern of the second opinion certainly obtained? Would the reason be related to the degree of trust in my physician? How can I evaluate the trust between my physician and me? Why?

- How could I regard my disease as a whole in terms of the past, present, and future? Can I see any good news as well as bad in what the doctor has told me? How can I possibly change the-bad-news-told to the-good-news?
- What is the cause to make me feel deeply unhappy compared with past? Why?
- Can I identify my genuine fear with words? How can I tell the physician or any appropriate person about such words? Why should I take such attitudes?
- What is right and what is not right in my specific problems right now? How can I go about such problems? Why have I not talked of the problems to anyone?
- What kind of new ideas and/or alternatives I possibly offer to my doctor and/or medical staff member in order to tackle with my disease? And Why?
- Is there any specific issue I want to tell my doctor, but I do not want to tell my family? Think of why, together with some reasons.
- What are my deeply buried problems of the disease not yet to have told to my family and my doctor? How can I begin to end such buried problems? Why am I still the prisoner of such problems?
- What kind of other questions at the crux of my life must be dealt with, before time is running out? How could my-will already written be acted out by whom? And why should I think of such issues right now?
- How could my own value system be fully understood by the family and the significant other before it is too late? Why might my own value system be considered strange and/or weird from my own family's perspective? Why can I and my family not manage to identify the pivotal points of difference in order to narrow down the gap before I have gone?
- How can my value system be utilized to overcome my pain and/or suffering up until the end of my own life?
- What is loneliness? Have I felt lonely even with my own family? Why? How can I end loneliness? How would the degree of loneliness differ when I am with my close friend? Can I analyse different kinds of loneliness surrounded by my daily life? How can I go about? Why should I focus such point? How would loneliness connect to psychology of my physical and mental health?
- Have I thought of how much I have been a burden to my family members as "family caregivers"? Have I told my sincere appreciation to them? If NOT, I must clearly express my genuine appreciation to every one of my family members helping me as "family

caregivers”. Think of the reasons why I should do so, because “family caregivers” must have had lots of stress, while taking care of me.

- In Japan where the tradition is to send presents to physician from patient and/or family of patient, should I ask my family to send some presents to my physician? Or, do I want to take any alternative way? This question is narrowed down to: Which way do I wish to take as a patient? Think of how to demonstrate my way between (1) showing intra-cultural difference in genuinely appreciating the physician by my saying: “Thank You So Much Indeed!!!” while having a good eye contact between the physician and me and (2) showing cultural awareness of mine by asking my family to send some presents to my physician at the appropriate timing.
- In order to accomplish my mission in life, before my death, how can I prioritize tasks so as to avoid missing the forest for the trees?

Being a chaplain, I have been privileged to talk with numerous patients at the end of life in the USA, the UK, and Japan. One thing in common or the universal phenomenon among patients, regardless of wherever the patient is quietly lying on the bed, is loneliness strongly felt at night when the darkness prevails, due primarily to many unsolved problems and worries over any bad news which might be told to him and/or her on the next day. Thus, I believe that the repertoire of virtue, i.e., being truthful, as chosen voluntarily by the patient, would be of help for checking the patient’s subjective fears as objectively as possible through the what, how, and why driven questions of CCC.

As the worst case scenario, any one would have to imagine and say, “Oh dear, God! I’ve got the sentence today from my doctor. I have terminal cancer on which I’ve been worried for a long time. My life expectancy would be for six months to live or so.” If that is the case, one panics and only later begins to calm down to think of numerous issues of psycho-socio-cultural-religious things as well as medical matters. Then, the question of quality of life would probably come up for how to spend the rest of one’s life. What is the quality of daily life to the patient at the end of life? In this respect, CCC helps the patient analyse the questions of what, how, and why.

In terms of my research question: “What do physicians tell terminal patients and/or the family of patients at the end of life with regard to the truth of diagnosis, treatment, and prognosis?”, I argue that the truth of the patient’s disease has tended to be the prerogative of physicians, rather than understood as something to be shared with patients and their families. Thus, every patient’s and/or family’s contribution, i.e., some symptoms of the patient so far buried and not yet told to

the physician, **is** expected to be scrutinized within the praxis of CCC and then told to the physician during the next interaction between them.

What I genuinely wish to explore as the central concerns in the thesis is to educate and/or empower the patient to maximally use their capacities as long as he/she lives. This means not to discriminate against dying persons only because of their physical deterioration at the end of life, but to respect patients as human beings with dignity up until the final end. The questions of: “How and Why to Show full Respect to the person?” can also be thought through by using CCC.

### **3.1.1.1 CCC in relation to the psychology of the patient at the end of life**

The psychology of truth-telling needs duly to be addressed for the patient at the end of life. In terms of how death and dying are oriented to the psychology of patient, the world-famous book written by Elisabeth Kubler-Ross M.D. clearly illustrated the five stages of the dying patient: the first stage of Denial and Isolation; the second stage of Anger; the third stage of Bargaining; the fourth stage of Depression; and the fifth stage of Acceptance. Dr. Kubler-Ross learned the importance of hope through Mr. J., the patient, who became like a philosopher, due to his long disease experiences. Hope was kept by the patient up until the very last day, such as, some cure may be found and new drug developed for the patient to become relieved from pain and suffering (Kubler-Ross, E., 1969: 138). From my own experience of caring for patients at the end of life I too believe that hope is of central importance for the patient’s wellbeing.

Thus, the psychological questions and concerns of the patient at the end of life include, i.e., What is my anxiety for remaining life? How can I overcome my fear of death? What allows me to avoid my anxiety? Where would my hope come from? How can I possibly create a new hope in the face of imminent death, and despite my fear of death? Here, as broadcast in January 2014, let me add what came from a report of BBC Radio 5 live: a dying patient said, “Death is an adventure” to her family. This is an interesting remark to create a new avenue rather than the convention: “Death is the dead-end period”, although the interpretation of the word, “adventure”, itself may vary depending on the knowledge and experience of the individual human being.

In order to help the patient understand, the physician should put his and/or her subjective idea of the patient’s disease into the patient’s perspective, bearing in mind the patient’s frame of mind, level of understanding, and wider context together with any related issues to this phenomenon. The Johari window is of help to figure out what can be seen and/or what cannot be seen between the interlocutors (physician and patient) in interactions on truth told.

The Johari window is below as a part of Professor Farber’s book entitled *Self-Disclosure in Psychotherapy* (Farber, B. 2006: 5).

	Known to Self	Not Known to Self
Known to Others	Open Self	Blind Self
Not Known to Others	Hidden Self	Unknown Self

The Johari window named after its two authors of Joseph Luft and Harry Ingham is to suggest the following four windows (Farber, B. 2006: 4 - 5) as useful for psychotherapy.

1. That which is known to both oneself and others (open).
2. That which is not known to others but is known to oneself (hidden).
3. That which is not known to oneself but is known to others (blind).
4. That which is not known to oneself nor others (unknown).

Along with the Johari window shown above, the questions of patient at the end of life are: What is within the section that no one can figure out / see among patient, family of patient, and physician and/or any staff member of medical team on the patient's disease at the end of life? How can anyone related to the patient help the patient see the blind section within the Johari window in order to help the patient reduce pain and suffering even at the end of life? Why would such attempt of finding the all blinded section be valuable and advisable for the patient at the end of life?

### 3.1.2 CCC applied to the family of the patient

One of the reasons for focusing on such "family caregivers" is that the present world-wide population of elderly people has been rapidly increasing, as it is pointed out below by R. Hebert and R. Schulz, in their conclusions of the article, "Caregiving at the end of life" in the Journal of Palliative Medicine. Vol. 9. No. 5. 2006: 1174 – 1187.

Family caregivers are indispensable to the care of seriously ill patients. Changing demographics, the trend toward outpatient care, and the increasing elderly population will render the care provided by families even more vital. However, their service often comes at a cost to their wellbeing. Clinicians need to be aware of caregivers' needs and intervene with those at risk (Hebert, R. and Schulz, R. 2006: 1182).

The role of the family of the patient at the end of life can be scrutinized by applying CCC. The questions, such as those posed below, – by both: (1) the individual person of the patient’s family using “I” and (2) the family using “we” – are expected to be followed by the meetings of all the members of the patient’s family. Here I would reiterate that the following questions are simply examples. Since each family has its own merits and demerits with regard to its approach to problems, because a number of families lead to the accumulated degrees of family driven problems.

- Have I, as the individual, and/or we, as the family, thought of the following concepts: the responsibility of patient and/or family, patient autonomy, patient’s making decision, quality of life, the quality of the patient’s daily life at the end of life, informed consent, respecting patient as human being, patient centered medical practice, and any other currently available concepts related to patient’s care at the end of life? If not, educate me and/or the family by reading books and/or visiting websites in the internet. Think of how to apply such concepts for the patient’s medical treatment and/or situation. Think of why I and/or we should learn these concepts for the patient of my family.
- Do I and/or we have the ability to evaluate the patient’s physical health and mental health objectively as well as subjectively? If I and/or we do not have such ability, think of how to objectively check myself and/or ourselves in terms of the knowledge and experience of the patient’s well-being. And ask myself and/or ourselves: Why should I and/or we focus on these elements? Who could help me and/or us analyse my and/or our own capacity objectively as well as subjectively?
- As the reasons to trigger the disease of the patient, have I and/or we warned to the patient about any habits enjoyed every day, i.e., smoking and drinking alcohol too much without doing diet and/or exercises?
- Have I and/or we told to and discussed with the patient about our family driven genetic problems? If not, think of how to tell to the patient. Why have I and/or we not told the patient about genetic problems up until now?
- Regarding the patient’s diagnosis, treatment, and prognosis, what are the crucial problems not yet talked between the patient and me as well as the family? Why?
- Have I and/or we obtained enough information from the doctor about the patient’s diagnosis, treatment, and prognosis in order to help me and/or the family ascertain the name of the patient’s disease? If not, think and begin the first step! Why Not?
- Have I and/or we tried to genuinely establish a good and trustworthy relationship with the doctor of the patient? If not, think of how to build trust relationship among the doctor,

any other staff of interdisciplinary team of the patient, the patient, me, and/or the family, before it is too late. Think further that the degree of trust between the physician and the patient, me, and/or the family might juxtapose with the degree of telling the truth from the physician to the patient, me, and/or the family.

- Is there anything secretly told from me and/or the family to the doctor of the patient, NOT to the patient? If so, think of how to begin any discussion with the patient. Or think of the reason of why NOT to begin anything at all.
- Have I and/or we experienced the change of relationship and/or the shift of power between the patient and the family including me? What are the examples of the power shift during the care of the patient? Think of how to solve such problems with the consideration of the human rights of the patient at the end of life. Why?
- For those who are “family caregivers”, have I individually and/or we ever thought of the care of the loved one as the burdens to me and/or us? Have I and/or we ever murmured: Oh ... the terminal care of the patient is terribly difficult indeed! Have I and/or we ever wanted to go honestly to any different place where there is no stress coming from taking care of the patient?
- Concerning consensus among the patient, me, and/or all the family members, are there any points that all of us have already reached our mutual agreement? How about the meaning of the quality of the patient’s daily life at the end of life? Here, check whether our mutual agreement has come or not in any aspect of the patient’s care at final stages.
- On the value system of the patient, have I and/or we understood the patient’s wish at the end of life? How about the patient’s wish about whether or not to use respirator? If not, how could any different understanding between the patient and the family members be sorted out towards the patient’s value? Why?
- In Japan, the key question about treatment at the end of life is: Has any one of family members checked whether the patient wants to use a respirator? This question is terribly important to ask, because to attach a respirator to patients at the end of life has been justified for a very long time as the discretion of Japanese medical doctors without any agreement of Japanese patients and their family members. This reflects the cultural assumptions of Japan, based upon the hierarchical society and reflected through strong medical paternalism. Numerous family members have got angry once their loved one had been placed by the physician under the control of a respirator, as was discussed in Chapter Four. Respirator driven reality should never be forgotten as a major problem of Japanese medical practice. Accordingly, it is expected to discuss about respirator with patient and



family members. And then to tell the physician of the patient about the wishes and/or decisions of both: the patient and the family whether or not respirator is expected used.

- In order to help accomplish the patient's mission in life, before his and/or her death, how can I and/or we prioritize tasks so as to avoid missing the forest for the trees?

### **3.1.3 CCC applied to the physician or medical team in regard to the patient facing death**

Physicians can vary depending on: (1) personality, (2) the motivation of why to choose to combat disease through interaction with patient and/or family of patient, (3) knowledge and experience in medical practice at any specific context, and (4) any other reasons. Thus, the following questions are just references to help the physician become a conscientious and/or thoughtful physician.

- Who am I as a human being? This question is terribly important to scrutinize myself objectively, rather than placing me in medical settings. How can I do this? Why is this worthwhile, since I am deadly busy every day with a variety of routines at hospital?
- Further to look at myself objectively, have I experienced any operation, pain, and suffering in any hospital? If so, remember the day of the operation in the past in order to help me sympathize with what any patient might have gone through: before and after the operation. If no such experience of an operation is found, think of me as the person who lacks the first-hand experience of any operation in the medical context. Thus, I need to develop empathy towards pain and suffering of patients.
- What are the reasons and/or motivations to make me study medicine to become a physician? Try to re-visit what kind of steps and/or processes I've taken so far.
- Have I understood medical jargon often used recently, i.e., patient-centered medical practice, patient autonomy, and treating the patient as a whole? If not, why am I NOT trying to grasp such concepts? Or, even if I somehow can understand their meanings, I still need to think of how to apply them for the individual patient, while pondering the reasons of "Why?". Remember not to use medical jargon in any interaction with patient and family of patient.
- Can I communicate well with patient and/or family of patient about telling the truth of patient's disease in terms of diagnosis, treatment, and prognosis? If I cannot, think of how to change my attitude with any appropriate words created for telling any bad news to patient and/or family. Think of the reasons of why I should take time to suddenly revise my language and body language.
- Have I ever thought of what is the content of the truth of the patient's disease? Have I consciously checked my way of the process about how to create the fullness of truth of the

patient's disease in terms of diagnosis, treatment, and prognosis? Why should I think of these issues just before the interaction of my new patient?

- In order to show my respect to the patient, have I tried to genuinely understand the value system of the patient, including the spirituality of the patient? Have I asked the patient about these things? If not, why?
- Have I ever thought of the patient as if he and/or she were the member of my own family? If I could have thought of the patient like that, could my interaction with the patient have been changed? Would my treatment of the patient have been revised? Must the life of the patient be extended in order to enjoy more time with the family of the patient?
- As a doctor, have I received any complaints from patients? If so, how have I responded to them? Why? Or, did I ignore any complaint from patient? If so, is that because I believe I am the authority in the treatment of the patient? Can I think and act out avoiding such proud attitude from today? Why?
- Evaluate myself with a scale of 1 to 10 in between the worst and the best physician. Try to become a good physician tomorrow, while thinking of how to go about right now. Why should I scrutinize my own daily conduct as objectively as possible?
- What mission should I have as a physician throughout my entire life? How should I go about it? Why?
- Which patient can I NOT forget? What are the reasons for NOT forgetting that particular patient? Why?
- Have I seriously considered the problems of “family caregivers” of patients? If not, think of the stress and burdens they must have gone through, while taking care of their loved ones. Think further how to help “family caregivers” out of their mental and physical problems.
- If I were a patient, what kind of physician I would want to have in terms of doctor's knowledge and experience of medicine, doctor's personality, and doctor's way of treating me as the patient in the interaction of telling the truth of my disease: diagnosis, treatment, and prognosis?
- In the Japanese medical climate, the concept of “key person” has emerged by medical staff trying to create the patient's focused daily life surrounded by the key person even in hospital settings. Is this system working well in how I interact with the patient and his or her loved ones?

- In order to help accomplish the patient's mission in life, before his and/or her death, how can I prioritize my responsibility for the patient so as to avoid missing the forest for the trees?

Here, let me introduce Francis Weld Peabody M.D., professor of Medicine, Harvard Medical School, USA, who advocated that physicians are expected to have interest in humanity as stated in his book titled *The Care of the Patient* published in 1928, as stated below:

The good physician knows his patients through and through, and his knowledge is bought dearly. Time, sympathy, and understanding must be lavishly dispensed, but the reward is to be found in that personal bond which forms the greatest satisfaction of the practice of medicine. One of the essential qualities of the clinician is interest in humanity, for the secret of the care of the patient is in caring for the patient (Peabody, F. 1928: 48).

Based on the great advice of Dr. Peabody, I would add: in a nutshell, the physician particularly should become interested in the humanity of the patient who is just about to die.

### **3.1.3.1 CCC and the virtuous physician**

In the hectic moments of the hospital setting, the interaction between the patient and the physician offers the real challenge for the physician of virtue to act out genuine virtue as quickly and effectively as possible for the patient. My question is: "Where is virtue driven ethics located within truth-telling medical practice?" The following are major statements of virtue as related to truth-telling medical practice:

- (1) Although intellectual virtue and moral virtue are both required for the best interests of the patient, clinical judgment has tended to focus on intellectual virtue only. Thus, moral virtue must equally be underlined for moral judgment duly made in clinical medicine (Pellegrino, E. and Thomasma, D. 1993: 84f.). The above statement is rooted in the concept of prudence of Thomas Aquinas.
- (2) For physicians to deal with the patient's disease, five virtues are necessary: "compassion, discernment, trustworthiness, integrity, and conscientiousness" (Beauchamp, T. and Childress, J. 2009: 38f.), with ethical concepts, veracity, confidentiality, privacy, and fidelity (Beauchamp, T. and Childress, J. 2009: 45 – 46) which are referred to by Hursthouse, R. 1999: 41.

- (3) The following are the eight virtues in medicine: fidelity to trust, compassion, phronesis (as medicine's indispensable virtue), justice, fortitude, temperance, integrity, and self-effacement (Pellegrino, E. and Thomasma, D. 1993: 65 – 161).
- (4) In patient care, trustworthiness is the key to medical virtue from the Hippocratic Oath to the AMA codes, as the basis of professional ethics (Dyer, A. 1985: 230f.).
- (5) What is required in terms of virtue from the patients' perspective? The key virtues required are fortitude, prudence, and hope, for the patient to cope with illnesses, pain, and suffering (Lebacqz, K. 1985: 278f.)

The virtue driven definitions stated above contain many philosophical and ethical vocabularies. Thus, I can see that medical ethics of physicians including their truth-telling practice is heavily indebted to the history of philosophy, i.e., Socrates, Plato, and Aristotle, and the history of Christian ethics, i.e., Saint Augustine and Thomas Aquinas. Thus, let me quote below the original statements of the philosophers and theologians par excellence as deeply intertwined with the physician's daily practice, including that of truth-telling.

With Aristotle's ethics of virtue in the *Nicomachean Ethics* rooted in the character of the agent (Aristotle, 1962: 1105a25-30), a virtuous person is defined acted out "at the right time, toward the right objects, toward the right people, for the right reasons, and in the right manner" (Aristotle, 1962: 1106B20-23). How difficult it is to become a virtuous physician of the right truth-telling to the right patient.

Based on practical wisdom ("phronesis") of two virtues: an intellectual or rational virtue of reason embedded, and an embedded non-rational character-oriented moral virtue obtained by training and/or habit, Aristotle said that "practical wisdom's most characteristic realization is good deliberation" (NE 1141b11), to seemingly suggest a good truth-telling expected. On practical wisdom vs. medicine, medical science is practical wisdom regarding *bodily welfare* (Erde, E. 1985: 207f.) followed by the interpretation of practical wisdom, as "phronesis" is the linchpin to Aristotle's theory of virtue (Stohr, K. 2006: 202).

"Phronesis" of discovering the right way and goal is interpreted embedded in the psychology of the person in action, i.e., only the qualified person can distinguish between good and not-good by his choice (Hursthouse, R. 1999: 28), the right conduct is based on the actual agent's motives (Slote, M. 2001: 5), virtue is rooted in "arete" ("excellence") of excellent character obtained by training, and Plato's conversation with Protagoras in Athens on good attributes of human beings

appear only in actions, as the contrast to ignorance and that courage must be the knowledge of no fear (Allen, J. 2006: 28f.). Thus, the psychology of the physician is the key certainly expected at truth-telling executed to the patient.

In Aristotle's virtues, courage is the virtuous mean between rashness (the excess of courage) and cowardice (the lack of courage). On the mean vs. moral competence, any person wishing to become morally competent must learn how to negotiate the mean of a traditional virtue, because competences do not display means, and moral competences need all things considered (Morton, A. 2006: 133f.). The moral competences considered are all anticipated for physician to tell truth appropriately to patient.

That Aristotle's virtue is anticipated to be learned by copying a noble person's behaviour is important in terms of good practice passed on from generation to generation. As Aristotle's concept of Mean properly measured with the person is different for different people (Atkins, E. and Williams, T. 2005: 102), truth-telling also can be scrutinized by two different persons' viewpoints: (1) the physician's perspective of truth told and (2) the patient's perspective of truth told. Here let me add what conscientious patients said, regardless in the UK, the USA, and Japan, that is "So far, I've met many physicians through my disease's problems. Therefore, I've developed a perception to differentiate between conscientious physician and bad physician". This statement can verify a universal nature of conscientious patients surely ascertained with "a noble person's behaviour" copied, as suggested above.

On virtue within Christianity, Saint Augustine in the 5<sup>th</sup> century defined virtue as the love of four factors: temperance, fortitude, justice, and prudence, whereas Thomas Aquinas (1225 – 1274), who agreed with the same four factors but claimed charity as the essence of virtue, advocated prudence, as the amalgam of Aristotle's virtues, along with supernatural virtues of charity, hope, and faith, based on revelation. Prudence is the ability of choosing the right means, the disposition of mind, and the action in order to attain an end (Westberg, D. 1994: 188f.). Prudence driven person has intellectual and moral virtues and that "prudence, correct practical reasoning, logically presupposes that the desires for ends have been made right by moral virtue" (Westberg, D. 1994: 218 – 219). Through the history of virtue with the major figures above, I can see how virtue helps mould physician's attribute and practice including truth-telling to patient.

I would argue that the virtues mentioned above are not the monopoly of physicians, but patients are also expected to apply the virtues. In medical settings, the questions beginning with "What, How, and Why?" of truth-telling at the end of life certainly exchanged between patient and physician would include: What does it really mean to have only six months to live? How can I digest such a reality that has just come into my life? Why can I not try to make six months be

extended longer? In terms of creative thinking with the disease at the end of life: What would be the alternative way to make one live with any hope without simply sticking to six months only to live? How could I create a healthy space between (1) the physiology of my human being (my current disease at the end of life) and (2) the psychology of my human being (my own feeling intertwined with my value system)? Why should I not try to create such a space / room for the rest of my life? What is virtue to me as patient? What is virtue driven truth-telling practice from me, the physician, to the patient? Both questions: (1) “how to go about virtue vs. truth-telling” and (2) “why?”, are expected to be pondered by both patient and physician, separately. These issues also apply to the wider group of people involved in the care of the patient, including family and hospital personnel.

### **3.1.4 CCC as applied to the Chaplain to the patient and/or family at the end of life**

Apart from knowledge and experience in traditional religion and its secular interpretation, the chaplain is expected to adopt a genuine attitude of listening to whatever the patient and/or family say. The responsibility of the chaplain within the interdisciplinary team of the patient is to accurately represent the value system of the patient (if needed, the value system of the family is also to be considered) to the medical team of the patient. Thus, the chaplain is anticipated to create an atmosphere of *agape*, unconditional love and/or thoughtful love, enough to help the patient and family feel safe about whatever they want to say.

Based on my experiences in being with patients, I have noticed that there are at least three kinds of patient’s utterances:

- Patient’s statement to voluntarily reveal his and/or her own value system, i.e., “I am very happy in this excellent hospital” stated by patients in the USA and Japan.
- Patient’s request for help or advice, i.e., “I need my three teeth at the front of my mouth fixed right before my open heart surgery in tomorrow morning!!!” Through taking his teeth driven worries very seriously, I told his physician about the patient’s urgent problem. Thus, his operation was postponed and the patient was instead taken to the dental hospital located next to the hospital. The patient had his operation two days later, after his three teeth were duly fixed.
- Patient’s statement to show the lack of interest and/or knowledge of conventional religion, i.e., a Japanese female patient said: “My parents were Christian, but they did not teach me about the Bible.”

Thus, the chaplain is expected to conscientiously think of how to begin “Greeting” with the patient before actually interacting with patient, because the first impression given with greeting from the chaplain to the patient is terribly important to eventually affect the atmosphere – either positive or negative – during interaction between the patient and the chaplain. Here, CCC is helpful for the chaplain to reflectively analyse his and/or her own thinking and/or conduct with questions listed below. Let me mention, however, that CCC based questions below could differ depending on: (1) the chaplain with his and/or her focus at the specific time with the patient, (2) the patient with the particular disease and unique character, and (3) any other reasons to make the chaplain change the ingredients of the questions.

Before any interaction with any patient, it is expected for any chaplain to ask himself and/or herself about who he and/or she is as a human being together with the questions below based on CCC, although the following are merely some examples.

- Who am I as a human being? Can I examine myself in the third person? How do I begin such a process? Why should I go through such a process as soon as possible?
- What kind of chaplain am I? If I am not good, I must try to create a good model to make me someone who can be ready for the patient and/or family at the end of life.
- Can I objectively as well as subjectively answer the questions, i.e., What is the responsibility of the patient and/or family?, How can I think and act out patient autonomy, the patient’s decision-making, and respect the patient as a human being?, What is the quality of daily life to patient at the end of life?, What are the appropriate philosophy and ethics of medicine and/or medical practice that I should learn and act out?, What does trust relationship mean between patient and chaplain? How can I best promote patient centered medical practice connected with “informed consent”?, What is meant by treating the patient as a whole, and how can I ensure that I do so?, What are any other relevant concepts related to patient care at the end of life?, If I do not have answers about these questions, I must educate myself of them by reading books and/or visiting websites on the internet. Think of how to apply these questions-driven concepts during the interaction between the patient and me, the chaplain. Reflect on why I should learn and then act out these concepts.

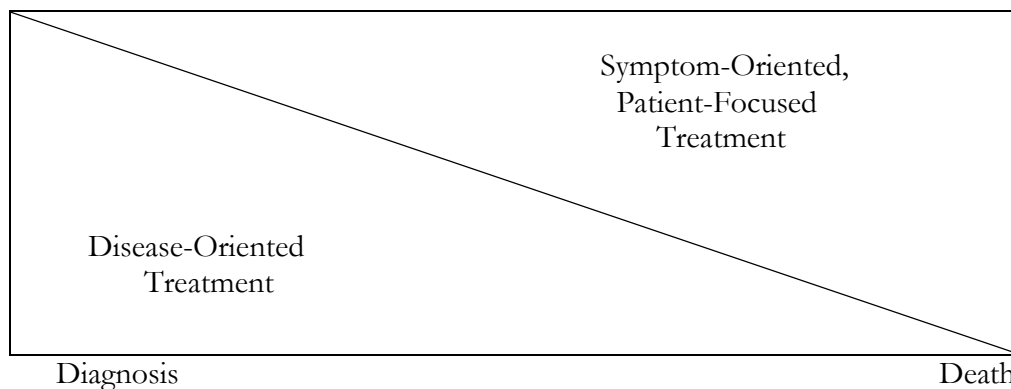
Then, let’s begin to think of any real interaction between the patient and me, the chaplain, with the questions listed below based on CCC.

- Generally speaking, what are the ingredients of a good greeting with patient? How do the language and body language of the chaplain by his and/or her greeting affect the flow of interaction with patient? Think of the reasons of Why?
- What would be in the patient's and/or family's mind? How could I acquire the knowledge and experience of how to figure out what are in their mind prior to asking them? Think of the reasons of Why?
- Generally speaking, when would be the appropriate timing to ask the patient and/or the family? How can I know such timing? For example, (1) regarding the patient's recognition of his or her own any change physically and/or mentally, to ask the patient: Have you experienced anything different physically and mentally since I met you last time? If so, please let me know, if you do not mind. I will then let your physician know about it, if you do not want to directly tell about it to your doctor; (2) in terms of the patient's religious history, to ask the patient: Do you have faith of special religion? Are you a member of a religion? Even if you do not belong to specific religion, if you have anything as your personal belief which you hang on to, would you please let me know, if you do not mind, about your own value system; (3) concerning how the patient's value system and/or ideas are related to his or her decision made, to ask the patient: About your relationship between thinking and making decisions, what are the key issues, i.e., people, places, priorities, whenever you have to make a decision?; and (4) In order to understand the patient's character and background, to ask the patient: What is a memory of a happy time to make you smile once again right now? What gives your life meaning? What helps you cope with stress and/or pain? Do you have a friend with whom you genuinely feel happy and talk a lot? Do you have a good relationship with your parents? How could you explain the relationship between you and every individual member of your family? Before you were hospitalized as a patient, did your family respect you and your decisions? If so, please tell me what kind of decision was accepted by your family. Is there any value system that you genuinely cherish and sincerely wish to pass on to next generation of your family and/or generation to generation?
- Have I seriously considered the problems of "family caregivers" of patients? If not, think of the anxiety, stress, and burdens they must have experienced, while taking care of their loved ones. Think of how religion would help them out in terms of changing their daily attitude to a positive one in communicating with the patient.
- In order to help accomplish the patient's mission in life, before his and/or her death, how can I prioritize my tasks for the patient and/or the family?



In 1926, Dr. R. Cabot, the physician, already mentioned on truth-telling in Chapter One, wrote that “For as I have known medical students and theological students, their ideals and hopes, they seem to me astonishingly alike. In each group the majority want to be of use to their kind, in man-to-man personal relations. A smaller number like to deal with crowds and to give them the healing truth” (Cabot, R. 1926: 1). This statement is seemingly to tell how important it is to understand the nature of pain and suffering of the patient in particular by the physician and the chaplain, because the patient is a human being with psycho-socio-cultural-religious problems as well as medical / disease driven problems. Thus, the patient at the end of life might not have the courage to speak up, but only to utter a little, just like a hoarse whisper that nobody might be able to hear.

Professor Janet Abraham M.D. at Harvard Medical School and division chief of Adult Palliative Care at Brigham & Women’s Hospital in Boston, Massachusetts in the USA wrote a book entitled *A Physician’s Guide to Pain and Symptom Management in Cancer Patients* in 2005 and pointed out the importance of the other aspects of the patient’s wellbeing, rather than only focusing on the medical aspect, at the time when the patient is approaching at the end of life, as quoted her chart below (Abraham, J. 2005: xvii).



Dr. Abraham also pointed out the importance of the chaplain’s role. An end-stage breast cancer patient, with her concern of what God’s attributes are, regained her religious belief in God, right after she had a dialogue with chaplain (Abraham, J. 2005: 85). Regarding the chaplain’s role and the measures of spirituality and spiritual well-being that are directly related to the quality of life among cancer patients, it is stated that “challenges remain in the areas of conceptualizing and measuring spirituality, developing and implementing training for spiritual care, and coordinating and partnering with chaplains and religious communities” (Peteet, J. et al.2013: 280) by CA Cancer J Clin 2013;63:280–289. ©2013 American Cancer Society.

### **3.2 How does CCC relate to medical practice in Japan?**

How does CCC relate to medical practice in Japan? More explicitly, in terms of the focus of this thesis: How might CCC help change Japanese medical culture in terms of truth-telling and its practice, and help transform the attitude of patient and/or family and physician and/or medical team? Japanese medical culture does not stand alone, but only exists as part of a much bigger context: the Japanese culture of traditional values embedded in every facet of Japanese daily life. Thus, thinking about the concept of truth-telling and its practice is also to inspect directly and/or indirectly what are the traditional values survived up until now in Japan. With all the circumstances considered, CCC can be used to examine both: (1) the understanding and practice of truth-telling within Japanese medical culture and (2) the wider Japanese culture and its long-standing traditional values, which still remain today.

Regarding how CCC relates to Japanese medical culture concerning the concept of truth-telling and its practice, CCC is a genuine attempt to allow the patient and/or every individual person connected to and/or concerned with the patient at the end of life to create the right question to ask himself and/or herself followed by his/her own investigation of what would be the right way to solve the patient's problem. This can take place while he/she, just like a good student of doing his and/or her own homework well, is unpacking both: (1) Japanese medical culture and its understanding and practice of truth-telling and (2) any other Japanese traditional values embedded in Japanese culture. This can be accomplished with reference to a variety of academic fields, their published research studies, and/or the internet, which provides world-wide information to compare between Japan and foreign countries about, i.e., patient autonomy, patient decision-making, patient-centered medical treatment, and/or the quality of the patient's daily life. Accordingly, the more the individual person has knowledge and experience of how to understand the truth of the patient's disease and the psycho-socio-cultural-religious facets of the patient, the more he and/or she can create the right questions and the right ways to solve the patient's problems.

In Japan there is the gap between recognising the value of a medical concept and its being put into practice. It takes a long time to make ordinary Japanese people understand the concept of truth-telling and its practice, due to the fact that Japanese hierarchical culture and medical paternalism are deeply embedded in everyday life and practices. These go hand-in-hand and/or are juxtaposed with each other so as to slow down or stymie the incorporation into Japanese medical practice the medical new waves and best practices from the West, such as patient autonomy etc.

Here, as an example of the tradition of Japan, I can revisit the notorious proverb of Japan: “The nail which stands up is hit back down,” as the product of this insular and conformist culture which resists change and innovation. This phenomenon is observed in every aspect of Japanese society. The following two notorious contexts urgently need to change: (1) the customary interaction and power struggles among family members over their loved one’s care at the end of life and (2) the typical lack of receptivity in classroom interaction among Japanese pupils towards learning new ideas from every individual.

Thus, CCC helps not only to pinpoint where the patient stands precisely, but also to question the place of Japanese medical culture within the framework of the Japanese culture of traditional values. I wish for each Japanese patient to end following blindly Japanese vertical medical tradition per se, to ensure that every patient’s voice is heard, based on CCC, not based on the patient’s own idiosyncratic values only. Likewise, the physician and/or medical team in Japan are anticipated to use CCC voluntarily to invest their own time to understand the scale of the patient’s problems.

Culture is a major factor influencing the physician in the definition of disease and truth-telling of patient’s diagnosis, treatment, and prognosis. Likewise, culture tends to affect the patient’s value and conduct. Here, let me introduce one of the long traditions of Japan: the culture of sending presents from one Japanese person to any other Japanese person in order to express “Thank You!”. Any present sent is to function as the vehicle to indirectly show and/or tell the sender’s appreciation to the person who receives the present. This Japanese culture also influences Japanese medical culture including the relationship between the patient and the physician. Accordingly, when a person happens to be hospitalized, the person as the patient is expected to think of what kind of present would be good to give to Dr. X, the patient’s physician, sent at any appropriate timing. Some family members of the patient have called the ward office where their loved one has been hospitalized and said: Would you please let me know about what would be the favourite present for Dr. X to receive from the family of the patient. Regardless of a variety of cultures as related to medical practice in our present global village, the issue of presents sent would never be the core of medical practice per se. In Japan, however, presents sent to physician can talk as to create an atmosphere of letting the physician of the patient acknowledge: The family of the patient is out there to be ready for any help to the patient who would go through whatever medical treatment executed by the physician and any other medical team. I have noticed that any conscientious physician in Japan is prone to send his thank-you-letter to the family of the patient, although the wife of the physician is customarily expected to send such a letter to the patient’s family.

Here, let me add that the tradition of presents always sent is never unrelated to and/or is juxtaposed with Japanese interaction between patient and physician. Strictly speaking, to directly say “Thank You!!” from one’s sincere heart to interlocutors with an appropriate eye contact should be acquired and practised by Japanese people as the basis of any human interaction as well as the most precious behaviour of identifying who he/she is as a human being. Along with unspoken and/or blurred contents embedded in interaction between interlocutors in Japan just like lukewarm communication, I wonder if the tradition of presents sent should be re-considered to prioritize truth-telling duly actualized to maintain the quality of daily life of the patient at the end of life in the 21<sup>st</sup> century.

In the Japanese medical climate, the concept of “key person” has emerged by medical staff to try to create the patient’s focused daily life surrounded by the key person even in hospital settings. Here, I wonder if physicians decide the key person of the patient based on their own observation only, along with their question: Who comes to the hospital most frequently to see the patient? Thus, their decision might be wrong, and they should venture to directly ask the patient the question: Who is the key person? With that in mind, I would like to suggest particularly to Japanese physicians: Please begin to understand and acquire the attitude of “willing suspension of your own belief” in order not to make a mistake by a quick decision of who is the right key person of the patient, with the reference to the phrase of “willing suspension of disbelief” coined by philosopher Samuel Coleridge and published in his *Biographia Literaria* in 1817.

Socio-cultural questions of patient at the end of life include, i.e., What is the difference between my own version of quality of life at the end of life and my Japanese country based norm of quality of life at the end of life? How can I go about my own way at the end of life as an intra-cultural difference of patient at the end of life? Why do I stick to my stubbornness even on the issue at the end of life? What are the differences between my morality / ethics at the end of life and my country oriented tradition of morality / ethics at the end of life? What would be world-wide morality / ethics as common good to be learned as patient at the end of life? I wonder if the history of human beings would be the great teacher to obtain: (a) what humane action of a physician is remembered and (b) what conscientious conduct of a patient remains passed on to people, regardless of physician or patient, from generation to generation.

Adopting “a holistic approach to the patient”, must accompany critical and creative contemplation not only to help ponder what is patient autonomy, but also to actualize a more focused and constructive interaction of the treatment and its options in regard to the patient’s disease, through somehow negotiating between patient and physician, although Japanese people

tend not to exercise negotiations in their daily life, in order to make each meeting of the patient's care at the end of life as "only once in one's own life-time".

One element that may help to transform (i) the paternalism that has dominated the approach of physicians in Japan and (ii) the inadequacy and lack of mutuality in interpersonal encounters between physicians and their patients is the greater number of female physicians now practicing medicine. In comparison with the history of medical practice dominated by male physicians, the increase in the number of female physicians has contributed not only to the equilibrium of genders among physicians, but also to a better and more representative health service that caters for everyone, given the fact that a half of human beings are female. Along with female physicians certainly increased, I genuinely wish that Japanese female medical doctors become empowered so as to change medical culture in Japan for actualising truth-telling of diagnosis, treatment, and prognosis to Japanese patients at the end of life.

CCC is of value for everyone to practice in his/her own daily life at any given time, such as before and after any interaction with any other Japanese in every context. In summary, I hope that CCC can help Japanese people become aware of the need to unpack not only medical culture and its practice, but also Japanese traditional values and their practices in order to check out which Japanese medical value / practice and/or Japanese traditional value / practice should remain valid today, and which Japanese tradition needs to change or disappear to suit our contemporary context and needs.

### **3.3 How is death, in its individual & universal meanings, grasped through CCC?**

In terms of truth-telling around death, anyone who questions what life and death really mean can never have serenity, unless the search for what death means is somehow to begin to end through one's ample knowledge and consideration of death, i.e., what is the gravity or profundity of death, followed by exchanging views on death with his and/or her friends as well as reflectively observing one's own present living moment as precious within the limited life-time to be shared with friends. If one can see death as the opportunity to educate oneself, through acknowledging death as a part of God's plan which comes without any prior notice, one would distil the depth of death, I believe.

Being present with the dying person is the most precious moment of human life, and death might in this way be perceived as an invaluable gift. No one can figure out when and how death and dying are about to come. In order to avoid the hustle when death and dying come out of the blue, we must be well prepared, with consideration given to the ways that human dignity and patient autonomy are exercised differently by each person, if the quality of daily life of the patient

at the end of life is to be fully actualized. Without exception, we all are forced to go through powerlessness once death has approached, including physicians. Having said that, “death may be a blessing when severe and incurable illness strikes” (Davies, D. 2008: 126f.). I believe that death always makes any living creatures ponder how to live this-day with the question of “why?” I believe that death is not the end, but is the beginning of another relationship. We should not become the slave to, or should not be caught up by, the notion of “here and now”, due mainly to our being obsessed by any visible things right now, while omitting anything invisible to be appreciated. Rather, we should include the transcendent relationship as well between the person in another world and us temporarily staying in this world. In sum, the following statement by Michel Foucault who offered great insights into the relationship between power and oppressed people, patients included, is of help to digest the universal meaning of death:

Generally speaking, the experience of individuality in modern culture is bound up with that of death: from Holderlin’s Empedocles to Nietzsche’s Zarathustra, and on to Freudian man, an obstinate relation to death prescribes to the universal its singular face, and lends to each individual the power of being heard forever; the individual owes to death a meaning that does not cease with him (Foucault, M. 1973: 197).

In the Bible, John: 8:32 states: Then you will know the truth, and the truth will set you free. This passage reminds us that truth not only makes us free from worries, anxiety, and stress to obtain genuine happiness, but eventually helps create serenity in one’s inner self. As said in the Christian grace of thanksgiving, “Many thanks for every breath with His invisible hand. Amen”.

## **Conclusion to Chapter Five**

For truth-telling at the end of life in the medical context to be truly enacted, it is necessary to create an authentic encounter based on effective and trustful communication, interaction, and dialogue between the recipients and providers of medical care. In this chapter I have endeavored to identify the barriers that stand in the way of authentic interaction and truth-telling in the medical context, especially at end of life, and to propose some concrete ways that these blockages can be overcome. A central goal of any encounter between physician and patient must be the establishment and fostering of a trusting relationship. This allows for full and frank discussion of the medical factors relevant to the patient’s illness, and it helps promote truth-telling in relation to diagnosis, treatment, and prognosis of disease. I have outlined some of the ways that trust can be promoted in the medical context. In addition, I have proposed that all those concerned with the best interests of the patient and his or her holistic care – which includes psycho-social, spiritual and mental wellbeing, as well as physical wellbeing – could improve the quality of encounters and

interactions in the medical setting by adopting a reflective practice of creative and critical contemplation.

CCC allows for self-examination before, during, and after conversations and decision-making about patient care. CCC can be adopted by all those involved in patient care and concerned about the patient's wellbeing – including the patient himself or herself. I have outlined a number of scenarios to show how CCC might be applied in: (i) the context of the patient; (ii) the context of the family; (iii) the context of the physician; and (iv) the context of the chaplain. This does not exhaust the types of person who might be involved in patient care. Instead, it offers some illustrative examples of what sort of questions to the self might be posed and pondered by the individual in question. Thus, the individual person is anticipated to become the responsible agent for his or her own decision made about the end of life care in order to avoid any murmurings: “I should have pondered and done X”. In order to educate oneself on his or her own, critical and creative contemplation (“CCC”) is of help before and/or after interaction about truth-telling of diagnosis, treatment, and prognosis of his or her disease at the end of life.

A central concern of this thesis is the culture of medical practice in Japan and the effects this has on patient autonomy and truth-telling to patients, especially in respect of end of life care. I have, therefore, suggested how CCC could help foster better patient care in the context of Japan.

## **A proposed conclusion within the limits of the present work**

This thesis has sought to investigate the concept and practice of truth-telling in medical settings. It has examined the literature on truth-telling in medicine, focussing on studies and research conducted in the USA, the UK, and Japan since the turn of the twentieth-century to the present day. In particular, the thesis has investigated the concept and practice of truth-telling in Japan, especially in terms of end of life care.

### **Key findings**

As the literature review indicates, from the turn of the twentieth century to the present day, a shift occurs – especially in the West – away from medical paternalism towards patient-centered medical care. This presupposes the disclosure of full information to patients who are expected to have a say in their treatment programmes rather than passively accept the judgments of their physicians. This has influenced the understanding and practice of truth-telling in medicine. The thesis argues that, as a result of this shift towards patient empowerment, truth-telling in medicine is more highly valued today than in previous eras. This is because today there is greater emphasis on patient autonomy and self-determination, rooted in respect for the dignity of the human person. I believe the changes of the United Nations and American society on the dignity of human beings and the human rights movement, from the post-war era of World War II in the 1940s, immensely contributed to enhancing the individual human being treated as equal on the worldwide scale, regardless of any different physical conditions, whether sick or healthy. Thus, truth-telling has become recognized as vital in allowing patients to act autonomously. The patient has a right to know the truth about their medical condition so that they can execute the various important decisions about their treatment, care, and wellbeing. This is all the more important at the end of life when the person must make their peace with the world and in their relationships.

In reality, however, it takes a long time to diffuse an accepted medical concept such as truth-telling down to the practice of people at the grass-roots level. In terms of interaction between patient and physician over truth-telling of a patient's disease, many complex problems still remain unresolved. Thus, I wonder if education of an accepted medical concept such as truth-telling to ordinary people would be necessary not only to let them think of a new wave of medical concept followed by its practice in medical settings, but also to help hasten a new medical concept with its practice down to real medical settings together with the understanding of people in general.



As this thesis has shown, in Japan the patient at the end of life may still be shielded from knowing the truth of their medical condition by the physician and/or their family carer. This is due to the continuing presence of strong cultural traditions that preserve family decision-making and medical paternalism over patient autonomy. The result is that patients at the end of life may be ‘protected’ from knowing about their diagnosis or prognosis, and denied the opportunity to make decisions about their treatment or the withholding or withdrawing of it, by well-meaning others. This is because, in Japan, medical paternalism is intertwined with Japanese vertical tradition, hierarchical values, and the family’s power which is heavily justified by paternalism. Truth-telling in medical practice is not an exception of such traditions in Japan, i.e. patients’ wishes are not customarily fulfilled at the end of life. In other words, Japanese traditional values have survived as part of the “present values of Japan”, and these values directly and indirectly affect the way in which truth-telling is acted out on patients and their families at the end of life. Truth-telling becomes more complicated, due to (1) the unequal footing in truth-telling driven interaction between Japanese patients and Japanese physicians and (2) problems of understanding imported vocabularies, i.e., individualism and patient autonomy.

Despite such a medical climate, some enlightened and candid Japanese physicians have courageously published books and/or explained their truth-telling related practices in medical journals to convince their fellow physicians, Japanese patients, and their families of the importance of truth-telling to facilitate patient autonomy and trust between patients and physicians. Failure to tell the truth to patients and their families concerned about the end of life has caused notorious lawsuits in Japan. Considering dignity around death, the Japan Society for Dying with Dignity has been popularising the concept of dignity through the promotion of living wills to facilitate the needs of the dying.

## **Recommendations**

A number of factors make it difficult for physicians and their patients to thoroughly discuss issues relating to illness and end of life care. Effective communication and truth-telling between patients and/or their families and medical personnel involved in end of life care could be improved in a variety of ways and contexts. In Chapter Five I identified the types of barriers that exist that prevent the necessary conversations taking place. I also proposed a number of ways to foster effective communication and truth-telling in medical settings, which can build trust between the interlocutors and maintain hope for the patient. Whether the truth is given to a patient depends on how much trust exists between physician and patient, accompanied by mutual consent. Thus, to engender trust between them, I suggest to both patient and physician that they apply a form of

reflective practice, critical and creative contemplation (“CCC”), before, during, and after interaction between them to objectively scrutinize the subjective thinking of each party, while trying to find alternative treatments and/or the most suitable care for the patient at the end of life.

I strongly wish that terminal patients and/or patients at the end of life should no longer be on the periphery of medical care. Any human being facing death / dying is expected to be treated with the appropriate respect due to human persons. The patient’s own psycho-socio-cultural-religious facets should be highly honoured rather than simply reduced to the medical aspects of diagnosis, treatment, and prognosis.

From many individual cases over the history of medicine the importance of truth-telling has emerged as a central principle in medical ethics. Together, humanity has learned from experience and distilled this into universally agreed medical practice to be applied to every one of us in our global village. Yet there is still much to learn about how to realise this concretely in the different cultures and contexts of medical practice, where the relationship between (a) trust and (b) interaction for communication among persons involved in patient’s end-of-life care is anticipated to be investigated, along with language, body language, and any other tangible and/or intangible cues. As a result, further development is envisaged in the concept of truth-telling and its practice in end of life medical care. Let us keep working hard to achieve that goal together for all of us, who will be patients sooner or later.

## Bibliography

Note: (ed./wtn.) means both editor and author.

- Abrahm, J. 2005. *A physician's guide to pain and symptom management in cancer patients*. Second Edition. The Johns Hopkins University Press. Baltimore, USA
- Aita, K. et al. 2007. "Physicians' attitudes about artificial feeding in older patients with severe cognitive impairment in Japan: a qualitative study." *BMC Geriatrics* 7: 22.
- Akabayashi, A. et al. 1999. "Truth telling in the case of a pessimistic diagnosis in Japan." *The Lancet*. 354: 1263.
- Akabayashi, A. 2002. "Euthanasia, assisted suicide, and cessation of life support: Japan's policy, law, and an analysis of whistle blowing in two recent mercy killing cases." *Social Science & Medicine*. 55: 517 – 527.
- Akabayashi, A. et al. 2003. "Perspectives on advance directives in Japanese society: A population-based questionnaire survey." *BMC Medical Ethics*. 4:5.
- Akabayashi, A. and Slingsby, B. 2006. "Informed Consent Revisited: Japan and the U.S." *The American Journal of Bioethics*. 6(1): 9 – 14.
- Akita, N. 2004. "Tan-kan-gan ni tsuite Ishira-ni Kokuchi, Setsumei Gimu-no Ihan wa Nakattato sareta Jirei." ("The case of the Verdict of No Negligence of the Medical Doctors' Truth-telling and Responsibility of Explanation to the Patient of Cholangio Cancer.") *Iryo Keiei Saizensen. Iji Gyomu-hen*. 5. 15 (No. 231). Sanro Sogo Kenkyujo. pp. 42 – 45.
- Allen, J. 2006. "Dialectic and virtue in Plato's Protagoras." In Reis, B. and Haffmans, S. (ed.). 2006. *The Virtuous Life in Greek Ethics*. Cambridge University Press. Cambridge. pp. 6f.
- Alvarez, W. 1931. "How Early Do Physicians Diagnose Cancer of the Stomach in Themselves? A study of the histories of forty-one cases." *JAMA*. Vol. 97, 2. 77 – 83.
- Alvarez, W. 1951. *The Neuroses: Diagnosis and management of functional disorders and minor psychoses*. Saunders Company. Philadelphia, USA
- Alvarez, W. 1952. "Care of the dying." *JAMA*. Vol. 150, 2: 86 – 91.
- Ammicht-Quinn, R. 2003. "Whose Dignity is Inviolable? Human Beings, Machines and the Discourse of Dignity." In Ammicht-Quinn, R. et al. (ed.) 2003. *The Discourse of Human Dignity*. Concilium. SCM Press. London. UK. pp. 35f.
- Anderlik, M. et al. 2000. "Revisiting the Truth-Telling Debate: A Study of Disclosure Practices at a Major Cancer Center." *The Journal of Clinical Ethics*. Vol. 11, 3: 251 – 259.
- Aristotle, 1962. Thomson. J. (trans.) 1962. *The Ethics of Aristotle: The Nicomachean Ethics*. Penguin Books.

- Arnold, R. and Egan, K. 2004. "Breaking the "bad" news to patients and families: preparing to have the conversation about end-of-life and hospice care." *American Journal of Geriatric Cardiology*. 13(6): 307 – 312.
- Asai, A. 1995. "Should Physicians Tell Patients the Truth?" *West J Med*. 163: 36 – 39.
- Asai, A. et al. 1997. "Medical decisions concerning the end of life: a discussion with Japanese physicians." *Journal of Medical Ethics*. 23: 323 – 327.
- Asai, A. et al. 1998(a) "Advance Directives and Other Medical Decisions Concerning the End of Life in Cancer Patients in Japan." *European Journal of Cancer*. 34(10): 1582 – 1586.
- Asai, A. et al. 1998(b) "Choices of Japanese Patients in the face of disagreement." *Bioethics*. 12(2): 162 – 172.
- Asai, A. et al. 1999. "Survey of Japanese physicians' attitudes towards the care of adult patients in persistent vegetative state." *Journal of Medical Ethics*. 25(4): 302 – 308.
- Asakura, K. 2007. "Iryo ni okeru communication." ("Communication in medical practice.") In Shimoda, M. et. al. 2007. *Iryo to Seimei: Ningenron no 21 seiki teki kadai. (Medical Practice and Life: the 21<sup>st</sup> century mission of the notion of human being.)* Nakanishiya Shuppan. Kyoto, Japan. pp. 32f.
- Atkins, E. and Williams, T. (ed.) 2005. *Thomas Aquinas: Disputed Questions on the Virtues*. Cambridge University Press. Cambridge, UK
- Bagaric, M. and Allan, J. 2006. "The Vacuous Concept of Dignity." *Journal of Human Rights*. 5: 257 – 270.
- Baier, A. 1994. *Moral Prejudices: Essays on Ethics*. Harvard University Press. Cambridge, MA, USA
- Baylis, F. and Downie, J. 2001. "Professional recommendations: disclosing facts and values." *Journal of Medical Ethics*. Vol. 27: 20 – 24.
- Beauchamp, T. and Childress, J. 2009. *Principles of Biomedical Ethics*. Sixth Edition. Oxford University Press. New York, USA
- Benn, P. 2001. "Medicine, lies and deceptions." *Journal of Medical Ethics*. Vol. 27: 130 – 134.
- Benn, S. 1976. "Freedom, Autonomy, and the Concept of a Person." *Proceedings of the Aristotelian Society*. LXXVI: 123 – 124.
- Berger, J. and Mohr, J. 1967. *A Fortunate Man: A Story of a Country Doctor*. Allen Lane The Penguin Press. London, UK
- Bible. 1997. The Bible: authorized King James Version / edited with an introduction and notes by Robert Carroll and Stephen Prickett. Oxford University Press. Oxford, UK

- Bito, S. and Asai, A. 2007. "Attitudes and behaviors of Japanese physicians concerning withholding and withdrawal of life-sustaining treatment for end-of-life patients: results from an Internet survey." *BMC Medical Ethics*. 8:7.
- Blackhall, L. et al. 1995. "Ethnicity and Attitudes Toward Patient Autonomy." *JAMA*. Vol. 274, 10. 820 – 825.
- Brewin, T. 1991. "Three ways of giving bad news." *The Lancet*. Vol. 337: 1207 – 1209.
- Buber, M. 1953. Smith, R. (trans.) *I and Thou by Martin Buber*. T. & T. Clark. Edinburgh, UK
- Buckley, J. 2008. *Palliative Care: An Integrated Approach*. Wiley-Blackwell. Chichester, UK
- Buckman, R. 1998. "Communication in palliative care: a practical guide." In Doyle, D. et al. (ed.) 1998. *Oxford Textbook of Palliative Medicine. Second Edition*. Oxford University Press. Oxford, UK. pp. 141 – 156.
- Bugge, C. et al. 2006. "The significance for decision-making of information that is not exchanged by patients and health professionals during consultations." *Social Science & Medicine*. Vol. 63: 2065 – 2078.
- Byrne, P. 1990. "Commentary 1. Comments on an obstructed death." *Journal of Medical Ethics*. Vol. 16: 88 – 89.
- Cabot, R. 1903. "The Use of Truth and Falsehood in Medicine: An Experimental Study." *American Medicine*. February 28: 344 – 349.
- Cabot, R. 1926. *Adventures on the Borderlands of Ethics*. Harper & Brothers Publishers. New York, USA
- Cabot, R. and Dicks, R. 1936. *The Art of Ministering To the Sick*. The MACMILLAN COMPANY. New York, USA
- Calman, K. 2002. "Communication of risk: choice, consent, and trust." *The Lancet*. 360: 166 – 168.
- Cardozo, L. et al. 1999. "The ethics of information disclosure in HIV disease and cancer: a study of medical residents attitudes." *Patient Education and Counseling*. Vol. 36: 75 – 80.
- Charlton, R. 1997. "The dilemma of truth disclosure: Stoke-on-Trent, England." *The American Journal of Hospice & Palliative Care*. July/August: 166 – 168.
- Christakis, N. 1995. *Prognostication and Death in Medical Thought and Practice*. A Dissertation in Sociology. The University of Pennsylvania, USA
- Coleridge, S. 1817. *Biographia Literaria*. In Engell, J. and Bate, W. (ed.) 1984. *Biographia Literaria*. Bollingen Series LXXV. Princeton University Press, USA

- Curtis, J. et al. 2002. "Patients' Perspectives on Physician Skill in End-of-Life Care." *Chest*. Vol. 122: 356 – 362.
- Daugherty, C. and Hlubocky, F. 2008. "What Are Terminally Ill Cancer Patients Told About Their Expected Deaths? A Study of Cancer Physicians' Self-Reports of Prognosis Disclosure." *Journal of Clinical Oncology*. Vol. 26, 36: 5988 – 5993.
- Davies, D. 2008. *The Theology of Death*. T&T Clark. London, UK
- Davis, A. and Konishi, E. 2000. "End-of-Life Ethical Issues in Japan." *Geriatric Nursing*. 21(2): 89 – 91.
- Dickenson, D. 2000. "Are medical ethicists out of touch? Practitioner attitudes in the US and UK towards decisions at the end of life." *Journal of Medical Ethics*. 26: 254 – 260.
- Drickamer, M. and Lachs, M. 1992. "Should patients with Alzheimer's disease be told their diagnosis?" *The New England Journal of Medicine*. April 2. 947 – 951.
- Dunbar, S. 1990. "An obstructed death and medical ethics." *Journal of Medical Ethics*. Vol. 16: 83 – 87.
- Dworkin, R. 1993. *Life's Dominion: An Argument About Abortion, Euthanasia, and Individual Freedom*. Oxford University Press. New York, USA
- Dyer, A. 1985. "Virtue and Medicine: A Physician's Analysis." In Shelp, E. (ed.) 1985. *Virtue and Medicine: Explorations in the Character of Medicine*. D. Reidel Publishing Company. Dordrecht, Holland. pp. 223f.
- Elian, M. and Dean, G. 1985. "To tell or not to tell the diagnosis of multiple sclerosis." *The Lancet*. Vol. 326: 27 – 28.
- Elwyn, T. et al. 2002. "Responsibility and cancer disclosure in Japan." *Social Science & Medicine*. 54: 281 – 293.
- Erde, E. 1985. "The Virtues of Medicine: Meaning and Import." In Shelp, E. (ed.) 1985. *Virtue and Medicine: Explorations in the Character of Medicine*. D. Reidel Publishing Company. Dordrecht, Holland. pp. 201f.
- Erde, E. et al. 1988. "On Truth Telling and the Diagnosis of Alzheimer's Disease." *The Journal of Family Practice*. Vol. 26, 4: 401 – 406.
- Faden, R. and Beauchamp, T. 1986. *A History and Theory of Informed Consent*. Oxford University Press. Oxford, UK
- Fallowfield, L. 1993. "Giving sad and bad news." *The Lancet*. Vol. 341: 476 – 478.
- Farber, B. 2006. *Self-Disclosure in Psychotherapy*. The Guilford Press. New York, USA
- Finkelstein, D. et al. 1997. "When a Physician Harms a Patient by a Medical Error: Ethical, Legal, and Risk-Management Considerations." *The Journal of Clinical Ethics*. Vol. 8, 4. 330 – 335.

- Fitts Jr., W. and Ravdin, I. 1953. "What Philadelphia physicians tell patients with cancer." *JAMA*. Vol. 153, 10: 901 – 904.
- Flannelly, K. et al. 2005. "Administrators' Views on the Importance of Various Chaplain Roles." *The Journal of Pastoral Care & Counseling*. Vol. 59. Nos. 1-2. Spring-Summer. pp. 87 – 96.
- Fleming, D. 1954. *William H. Welch and the Rise of Modern Medicine*. Little, Brown and Company. Boston, USA
- Fletcher, J. 1955. *Morals and Medicine*. Victor Gollancz Limited. London, UK
- Foucault, M. 1973. *The Birth of the Clinic: An Archaeology of Medical Perception*. Tavistock Publications. London, UK
- Fujimori, M. et al. 2007. "Japanese cancer patients' communication style preferences when receiving bad news." *Psycho-Oncology*. 16: 617 – 625.
- Fukuda, M. 2002. *Nihon no Shakai Bunka Kozo to Jinken*. (Japan's Social & Cultural Structures and Human Rights.) Akashi Shoten. Tokyo, Japan
- Fukuzawa, Y. 1960. Kiyooka, E. (trans.) 1960. *The Autobiography of Fukuzawa Yukichi*. The Hokuseido Press. Tokyo, Japan
- Gabbay, B. et al. 2005. "Negotiating End-of-Life Decision Making: A Comparison of Japanese and U.S. Residents' Approaches." *Academic Medicine*. 80(7): 617 – 621.
- Gan Kokuchi Manual. 2004. The National Institute of Cancer Research driven Hospital. <http://ganjoho.jp/professional/communication/communication01.html>.
- Gerle, B. et al. 1960. "The Patient with inoperable cancer from the psychiatric and social standpoints: A Study of 101 Cases." *Cancer*. Vol. 13. 1206 – 1217.
- Glaser, B. and Strauss, A. 1966. *Awareness of Dying*. Weidenfeld and Nicolson. London, UK
- Good, M. et al. 1990. "American Oncology and the Discourse on Hope." *Culture, Medicine, and Psychiatry*. Vol. 14: 59 – 79.
- Grell, O. 1993. "Conflicting Duties: Plague and the Obligations of Early Modern Physicians towards Patients and Commonwealth in England and the Netherlands." In Wear, A. et al. (ed.) 1993. *Doctors and Ethics: the Earlier Historical Setting of Professional Ethics*. Rodopi B.V., Amsterdam. pp. 131 – 152.
- Hancock, K. et al. 2007. "Truth-telling in discussing prognosis in advanced life-limiting illnesses: a systematic review." *Palliative Medicine*. Vol. 21: 507 – 517.
- Hayashi, M. et al. 2000. "Respecting Autonomy in Difficult Medical Settings: A Questionnaire Study in Japan." *Ethics & Behavior*. 10(1): 51 – 63.
- Hebert, P. et al. 1997. "Bioethics for clinicians: 7. Truth telling." *Canadian Medical Association Journal*. Vol. 156, 2: 225 – 228.

- Hebert, P. et al. 2001. "Bioethics for clinicians: 23 Disclosure of medical error." *Canadian Medical Association Journal*. Vol. 164, 4: 509 – 513.
- Hebert, R. and Schulz, R. 2006. "Caregiving at the end of life." *Journal of Palliative Medicine*. Vol. 9. No. 5. pp. 1174 – 1187.
- Henderson, L. 1935. "Physician and Patient as a Social System." *New England Journal of Medicine*. Vol. 212, 18: 819 – 823.
- Higgs, R. 1990. "Commentary 2. An obstructed death and medical ethics." *Journal of Medical Ethics*. Vol. 16: 90 – 92.
- Hinohara, S. 2007. "Yamuhito no Inochi no Songen to sono Inochi eno Tekisetsuna Taio." ("The Dignity of Life of Patients and the Appropriate Treatment to their Life.") *The Journal of the Japanese Society of Intensive Care Medicine*. Vol. 14, Supplement, January. p. 95.
- Hirai, K. et al. 2006. "makki gan kanja e no byomei kokuchi to communication no genjo: makki gan kanja no kaigo keiken ga aru izoku ni taisuru chosa yori." ("An Opinion Survey for Truth Disclosure and Communication in Bereaved Caregivers of Terminally Ill Cancer Patients."). *Kanwa Care*. Vol. 16, 2. pp. 179 – 184.
- Hirao, Y. 2004. "Shitsumon Box. Byomei kokuchi naki Gan-kanja ni naniwo kangoshiga kiotsukeru bekideshoka?" ("Question: What kind of problems should nurses consider when they have to face the cancer patients whose cancer has not yet been told?") *The Japanese language driven Journal called Urological Nursing*. Vol. 9, No. 3. pp. (289) 87 – (291) 89.
- Hirose, T. 2000. *Shi no Igaku: Yoi shini kata, shinase kata. (Medical investigation of Death: how to die well & to let die.)* Gakuseisha. Tokyo, Japan
- Holland, J. et al. 1987. "An International Survey of Physician Attitudes and Practice in Regard to Revealing the Diagnosis of Cancer." *Cancer Investigation*. Vol. 5, 2: 151 – 154.
- Horwitz, L. and Detsky, A. 2011. "Physician Communication in the 21<sup>st</sup> Century: To Talk or to Text?" *JAMA*. Vol. 305, No. 11, 1128 – 1129.
- Hosaka, M. 1993. *Anrakushi to Songenshi: Iryo no naka no Sei to Shi. (Euthanasia and Dying with Dignity: Life and Death within Medical Practice.)* Kodansha. Tokyo, Japan
- Hoshino, K. 1995. "Autonomous Decision Making and Japanese Tradition." *Cambridge Quarterly of Healthcare Ethics*. 4: 71 – 74.
- Hoshino, K. 1996, Heisei 8<sup>th</sup> year. *Watashi no Inochi wa Dare no Mono. (My life: To whom does this belong?)* Okurasho Insatsukyoku. Tokyo, Japan
- Hoshino, K. 1997, Heisei 9<sup>th</sup> year. *Informed Consent: Nihon ni Naresomu 6-tsu no Teigen. (Informed Consent: Six suggestions to spread in Japan.)* Maruzen. Tokyo, Japan



- Hursthouse, R. 1999. *On Virtue Ethics*. Oxford University Press. Oxford, UK
- Igata, A. 2004. “Nihon Songenshi Kyokai no ayumi to tenbo.” (“The History and Future Prospects of the Japan Society for Dying with Dignity.”) In *Shi no Kenri Kyokai Sekai Rengo Dai 15 kai Taikai. Kaisai Report. (The Opening Speech of the 15<sup>th</sup> World Association of Right to Die.)* Nihon Songenshi Kyokai. Tokyo, Japan
- Igata, A. 2006. “Songenshi ni miru Ishi Kanja Kankei: Kanja no Ishi wo chushin ni.” (“Physician and Patient Relationship seen in Dying with Dignity: with the focus on the patient’s wish.”) *Nihon Ishikai Zasshi*. 135(7): 1529 – 1533.
- Iizuka, K. 1952, Showa 27<sup>th</sup> year. *Nihon no Seishinteki Fudo. (Mental Climate of Japan.)* Iwanami Shoten. Tokyo, Japan
- Inaba, K. 2007. “Shumatsuki ni okeru Ho to Hanrei.” (“The Law and Verdict of the End of Life.”) In Takahashi, T. and Asai A. (ed.) 2007. *Nihon no Seimei Rinri: Kaiko to Tenbo. (The Bioethics of Japan: in the past and the future.)* Kyushu Daigaku Shuppan. Fukuoka, Japan. pp. 209f.
- Ingelfinger, F. 1980. “Arrogance.” *The New England Journal of Medicine*. Vol. 303, 26: 1507 – 1511.
- Ishiwata, R. and Sakai, A. 1994. “The Physician-Patient Relationship and Medical Ethics in Japan.” *Cambridge Quarterly of Healthcare Ethics*. 3: 60 – 66.
- Isogawa, N. 2003. “Makki Gan Kanja no Kazoku ni taisuru Ishi no Kokuchi Gimu – Ijiho no Ugoki (1).” (“Medical Doctor’s Responsibility for Truth-telling to the Family of the Terminal Cancer Patient - the change of medical law (1).”) *Nihon Iji Shinpo*. No. 4139. pp. 53 – 57.
- Iwase, S. et al. 2004. “Kokuchi wo meguru Sho-mondai.” (“Truth-telling driven various Problems.”) The Japanese language driven Journal called *Gerontology*. Vol. 16, No. 4. pp. 46 (312) – 48 (314).
- Japan Medical Association. “Nihon Ishikai.” 2004. “Ishi no Shokugyo Rinri Shishin.” (“The Guideline of Ethics to Physicians.”) *Nihon Ishikai Zasshi*. 131(7): 1 – 46.
- Japan Medical Association. “Nihon Ishikai.” 2008. *The Guideline on End-of-Life driven Medical Treatment*. February, 2008.
- Japan Society for Dying with Dignity. “Nihon Songenshi Kyokai.” [日本尊厳死協会](http://www.songenshi-kyokai.com). Hongo, Bunkyo-ku, Tokyo, Japan. [www.songenshi-kyokai.com](http://www.songenshi-kyokai.com)
- Jenkins, V. et al. 2001. “Information needs of patients with cancer: results from a large study in UK cancer centres.” *British Journal of Cancer*. Vol. 84, 1: 48 – 51.
- Jinko Mondai Chosakai (The Survey of Population driven Problems). 1988, Showa 63<sup>rd</sup> year. “Dai 19-kai Zenkoku Kazoku Keikaku Seron Chosa. Hokokusho.” (“The Report of the 19<sup>th</sup> Survey in all parts of Japan: on people’s opinions on family planning.”) *The Mainichi Newspaper*. Tokyo, Japan. pp. 78f.

- Kant, I. 1998. Gregor, M. (translated and edited) 1998. *Groundwork of the Metaphysics of Morals*. Cambridge University Press.
- Kaplowitz, S. et al. 1999. "Physician Communication with Seriously Ill Cancer Patients: Results of a Survey of Physicians." In Vries, B. (ed.) 1999. *End of Life Issues: Interdisciplinary and Multidimensional Perspectives*. Springer Publishing Company, Inc. New York, USA. pp. 205 – 227.
- Kashiwagi, T. 1978. *Shi ni Yuku Hitobito no Care*. (Care of People Who are about to Die Shortly.) Igaku Shoin. Tokyo, Japan
- Kashiwagi, T. 1999. "Truth Telling and Palliative Medicine." *Internal Medicine*. 38(2): 190 – 192.
- Kashiwagi, T. 2004. "Koreisha no Kanwa Care." ("The Palliative Medicine of Elderly Patients.") The Japanese language driven Journal called *Gerontology*. Vol. 16, No. 4. pp. 49 (315) – 51 (317).
- Kashiwagi, Y. 2003. "yomei kokuchi-go gan kanja eno kokan-note wo mochiita sekkyokuteki keicho." ("A Note of Exchanging Views, as the vehicle of active listening, between the cancer patient of the prognosis told and the nurse.") *Shi no Rinsbo*. 26, 2. p. 217.
- Kato, G. 2008. "SHI wo Dou shiraseru ka: Saizen no Ishikettei wo michibiku tameni." ("How to tell Death: to help the best decision made.") The Japanese language driven Journal called *International Nursing Review*. Vol. 31. No. 2: 39 – 42.
- Katz, J. 1984. *The Silent World of Doctor and Patient*. The Free Press. New York, USA
- Katz, S. et al. 1963. "Studies of Illness in the Aged." *JAMA*. Vol. 185, 12: 914 – 919.
- Kawakami, T. (ed.) 2002. *Sengo Nihon Byonin-shi*. (The History of patients in Japan: After World War II.) No-bun-kyo. Tokyo, Japan
- Kelly, W. et al. 1950. "Do cancer patients want to be told?" *Surgery*. Vol. 27, 6: 822 – 826.
- Kikui, K. et al. 2008. *Keesu de manabu Iryo Fukushi no Rinri*. (Ethics of Medical Welfare learned from real cases.) Igaku Shoin. Tokyo, Japan
- Kinjo, K. 1986. *Kazoku to iu kankei*. (The Relationship called "the Family".) Iwanami Shoten. Tokyo. Japan
- Kinoshita, S. 2007. "Respecting the Wishes of Patients in Intensive Care Units." *Nursing Ethics*. Vol. 14 (5). pp. 651 – 664.
- Kirchhoffer, D. 2009. "Become What You Are: On the Value of the Concept of Human Dignity as an Ethical Criterion in Light of Contemporary Critiques." from the DRAFT, before being published in *Bijdragen: International Journal in Philosophy and Theology*. 2009. Vol. 70, Issue 1. pp. 45 – 66.

- Koffman, J. et al. 2007. "Demographic factors and awareness of palliative care and related services." *Palliative Medicine*. 21(2): 145 – 153.
- Konishi, E. and Davis, A. 1999. "Japanese nurses' perceptions about disclosure of information at the patients' end of life." *Nursing & Health Sciences*. 1: 179 – 187.
- Kono, T. 1988. "Gan no Kokuchi." ("Cancer-Telling to the patients.") *Kyoiku to Igaku*. Keio Tsushin. Tokyo, Japan. pp. 41 (851) – 47 (857).
- Koyanagi, Y. et al. 2006. "sei to shi no kattou ga sonzai shinagaramo gan to mukiau koto ga dekite iru kanja no shinri wo saguru." ("A Study of the psychology of the patient who can face cancer, although the patient experiences struggles between life and death."). *The 37<sup>th</sup> Kango Sogo*. pp. 122 – 124.
- Krist, A. and Woolf, S. 2011. "A Vision for Patient-Centered Health Information Systems." *JAMA*. Vol. 305, No. 3, 300 – 301.
- Kubler-Ross, E. 1969. *On Death and Dying*. Tavistock Publications. London, UK
- Kuroyanagi, T. 2003. *Iryo Jiko to Shiho Handan. (Medical Practice based Accident and Legal Judgement.)* Hanrei Times. Tokyo, Japan
- Kuroyanagi, Y. 1994. *Songenshi wo kangaeru. (Scrutinizing Dying with Dignity.)* Iwanami Shoten. Tokyo, Japan
- Kuwabara, H. et al. 2005. "Hoteki Juyosei kara mita Gan Kokuchi to Informed Consent." ("Cancer-telling and Informed Consent from Legal Viewpoint.") *Ringai*. Vol. 60. No. 9. pp. 1093 – 1097.
- Leake, C. 1975. *Percival's Medical Ethics*. Robert E. Krieger Publishing Company. New York, USA
- Lebacqz, K. 1985. "The Virtuous Patient." In Shelp, E. (ed.) 1985. *Virtue and Medicine: Explorations in the Character of Medicine*. D. Reidel Publishing Company. Dordrecht, Holland. pp. 275 – 288.
- Lewis, D. and Anthony, D. 2007. "A patient and carer survey in a community clinical nurse specialist service." *International Journal of Palliative Nursing*. 13(5): 230 – 236.
- Leydon, G. et al. 2000. "Cancer patients' information needs and information seeking behaviour: in depth interview study." *BMJ*. Vol. 320, 1 April: 909 – 913.
- Life Design Institute (LDI). 2002. "Hospice no Genjyo." ("The Present Status quo of Hospice.") *LDI Report*. Tokyo, Japan
- Lind, S. et al. 1989. "Telling the Diagnosis of Cancer." *Journal of Clinical Oncology*. Vol. 7, 5: 583 – 589.
- Long, S. 2000. "Public Passages, Personal Passages, and Reluctant Passages: Notes on Investigating Cancer Disclosure Practices in Japan." *Journal of Medical Humanities*. 21(1): 3 – 13.

- Long, S. and Long, B. 1982. "Curable cancers and fatal ulcers. Attitudes toward cancer in Japan." *Social Science & Medicine*. 16(24): 2101 – 2108.
- Lund, C. 1946. "The Doctor, The Patient, and The Truth." *Annals of Internal Medicine*. Vol. 24, 6: 955 – 959.
- Macklin, R. 1982. *Man, Mind, and Morality: The Ethics of Behavior Control*. Prentice-Hall. Englewood Cliffs, NJ, USA
- Macklin, R. 1999. *Against Relativism: Cultural Diversity and the Search for Ethical Universals in Medicine*. Oxford University Press. New York, USA
- Maeda, Y. et al. 2006. "Psychological process from hospitalization to death among uninformed terminal liver cancer patients in Japan." *BMC Palliative Care*. 5: 6.
- Mariner, W. 1997. "Health Law and Ethics: Physician Assisted Suicide and the Supreme Court: Putting the Constitutional Claim to Rest." *American Journal of Public Health*. 87 (12): 2058 – 2062.
- Matsuyama, R. et al. 2006. "Why Do Patients Choose Chemotherapy Near the End of Life? A Review of the Perspective of Those Facing Death From Cancer." *Journal of Clinical Oncology*. 24(21): 3490 – 3496.
- McDonald-Scott, P. et al. 1992. "Diagnostic disclosure: a tale in two cultures." *Psychological Medicine*. Vol. 22. pp. 147 – 157.
- Medicine and the Law. 1949. "Surgeon's Successful Appeal." *The Lancet*. Vol. 1. p. 586.
- Meguro, Y. 1987. *Kojinka suru Kazoku. (The individualization of the Japanese family.)* Keiso Shobo. Tokyo, Japan
- Meulenberg, T. and Schotsmans, P. (ed.) 2005. "The Sanctity of Autonomy? Transcending the opposition between a Quality of Life and a Sanctity of Life Ethic." In Schotsmans, P. and Meulenberg, T. (ed.) 2005. *Euthanasia and Palliative Care in the Low Countries*. Peeters. Leuven. pp. 121 – 146.
- Meyer, B. 1958. "Some Psychiatric Aspects of Surgical Practice." *Psychosomatic Medicine*. Vol. 20, 3: 203 – 214.
- Mill, J. S. 1998. *On Liberty and Other Essays*. Oxford University Press. Oxford, UK
- Minami, H. 1953, Showa 28<sup>th</sup> year. *Nihonjin no Shinri. (The Psychology of Japanese People.)* Iwanami Shoten. Tokyo, Japan
- Ministry of Health and Welfare of Japan. 1989. In Hiraga, K. (ed.) *Annual Report of the Cancer Research (1-30)*. pp. 117 – 124.
- Ministry of Health, Labour and Welfare of Japan. 2005. *Death with dignity questionnaire research*.

- Ministry of Health, Labour and Welfare of Japan. 2008.  
*The Investigation of End-of-Life Medical Treatment*. March, 2008.
- Minooka, M. and Inaba, K. 2008. *Keesu kara manabu Koreisha Care ni okeru Kaigo Rinri*. (The Ethics of Nursing Care for elderly patients learned from real cases.) Ishiyaku Shuppan. Tokyo, Japan
- Mitsui, M. 2003. *Anrakushi no dekiru Kuni*. (The country where Euthanasia is allowed.) Shinchosha. Tokyo, Japan
- Mitsuya, H. 1997. "Telling the Truth to Cancer Patients and Patients with HIV-1 Infection in Japan." *Annals of the New York Academy of Sciences*. Vol. 809. Issue 1. February. pp. 279 – 289.
- Miura, H. and Ota, T. 2007. "Koreisha no shumatsuki iryo: rinri dilemma wo norikoeru tameni." ("Medical practice for Elderly people at end-of-life: how to overcome ethical dilemma.") *Nippon Ronen Igakkai Zasshi*. 44(2): 162 – 164.
- Miyaji, N. 1993. "The Power of Compassion: Truth-Telling among American doctors in the care of dying patients." *Soc. Sci. Med.* Vol. 36, 3: 249 – 264.
- Miyamoto, T. 1995. *Wasurerareta Nihonjin*. (The Japanese forgotten.) Iwanami Shoten. Tokyo, Japan
- Miyanari, N. 2002. "Moruhine Chiryō." ("Morphine driven Treatment.") In Ogawa, M. (ed./wtn.) 2002. *Shinjitsu no Tsutae Sasaeru tameno Gan Kokuchi no Tebiki*. (Manual on Telling Truth of Cancer: for Truth told and Help provided.) Shinko Koeki Isho Shuppanbu. Tokyo, Japan. pp. 176 – 186.
- Miyasaka, M. 2005. *Iryo rinri gaku no hobo: gensoku, tejun, narrative*. (Methods of Medical Ethics: principle, process, and narrative.) Igaku Shoin. Tokyo, Japan
- Miyashita, M. et al. 2008. "Effect of a population-based educational intervention focusing on end-of-life home care, life-prolonging treatment and knowledge about palliative care." *Palliative Medicine*. 22: 376 – 382.
- Miyata, H. et al. 2005. "Disclosure preferences regarding cancer diagnosis and prognosis: to tell or not to tell?" *Journal of Medical Ethics*. 31: 447 – 451.
- Miyata, H. et al. 2006. "Survey of the general public's attitudes toward advance directives in Japan: How to respect patients' preferences." *BMC Medical Ethics*. 7:11.
- Mizukura, Y. and Koiso, T. 2006. "Makki Gan Kanja no Kazoku ni taisuru Byōjo nado no Kokuchi Gimū." ("The Responsibility of telling truth of disease and related issues to the family of the terminal cancer patient.") *Nihon Iji Shinpo*. No. 4272. pp. 75 – 81.
- Mizuno, M. et al. 2002. "Truth Disclosure of Cancer Diagnoses and Its Influence on Bereaved Japanese Families." *Cancer Nursing*. 25(5): 396 – 403.

- Mizushima, Y. et al. 2005. "zaitaku koreisha eno terminal care no arikata." ("Issues of Terminal Care for the Community-Dwelling Elderly.") *Ishikawa Journal of Nursing*. Vol. 2. pp. 7 – 14.
- Mori, O. 1953. *Takasebune*. Chikuma Nihon Bungaku Zenshu. Chikuma Shobo. Tokyo, Japan
- Morioka, K. 1993. *Gendai Kazoku Hendoron*. (*The changing notion of the contemporary family*.) Mineruva Shobo. Kyoto, Japan
- Morioka, Y. 2001. "Makki kanja ni taisuru Iryo no Rinri." ("The Ethics of Medical Practice to Terminally ill patients.") *Nihon Ishikai Zasshi*. 126(6): 833 – 845.
- Moros, D., Rhodes, R. et al. 1991. "Thinking Critically in Medicine and its Ethics: relating applied science and applied ethics." In Almond, B. and Hill, D. (ed.) 1991. *Applied Philosophy: Morals and Metaphysics in Contemporary Debate*. Routledge. London, UK. pp. 245 – 259.
- Morton, A. 2006. "Moral Incompetence." In Chappell, T. (ed.) 2006. *Values and Virtues: Aristotelianism in Contemporary Ethics*. Oxford University Press. New York, USA. pp.118f.
- Mouri, K. 1985, Showa 60<sup>th</sup> year. *Sei to Shi no Sakai*. (*The Boundary between Life and Death*.) Tokyo Shoseki. Tokyo, Japan
- Muller, J. and Koenig, B. 1988. "On the boundary of life and death: the definition of dying by medical residents." In Lock, M. and Gordon, D. (ed.) 1988. *Biomedicine Examined*. Kluwer Academic Publishers. Dordrecht. pp. 351 – 374.
- Murray, S. et al. 2002. "Dying of lung cancer or cardiac failure: prospective qualitative interview study of patients and their carers in the community." *BMJ*. Vol. 325. 26 October. pp. 1 – 5.
- Murray, S. et al. 2003. "Dying from cancer in developed and developing countries: lessons from two qualitative interview studies of patients and their carers." *BMJ*. Vol. 326. 15 February. pp. 1f.
- Muto, K. 2003. "yomei wazuka dearu kotonno tsutae kata." ("How to tell the patient's life remains for only a short time.") *Shi no Rinsbo*. Vol. 26. No. 2. Ippan endai (23) – 4.
- Nabekura, I. 2007. "ima futatabi 'gan kokuchi no arikata' wo tou: kirisuto-kyo ni okeru SHI no kyoiku no shiten kara." ("Asking right now once again how telling-cancer should be like: from Christian Perspective of Death Education.") *The Journal of Seinan Jogakuin University*. Vol. 11: 123 – 132.
- Nakane, C. 1970. *Japanese Society*. Weidenfeld and Nicolson. London, UK
- Ngo-Metzger, Q. et al. 2008. "End-of-Life care: guidelines for patient-centered communication." *American Family Physician*. 77(2): 167 – 174.
- Niimi, I. 1984. "Ishi to Kanja no Kankei." ("Relationship between physician and patient.") In Kato, I. and Morishima, A. (ed.) 1984. *Iryo to Jinken*. (*Medical Practice and Human Rights*.) Yuhikaku. Tokyo, Japan. pp. 83 – 155.

- Nishikawa, K. 1982. *Kagayake naga Inochi no Hibi yo: Gan wo Senkoku sareta Seishinka-i no 1000 nichi.* (Let my life shine in the remaining days: 1000 days of the psychiatrist whose cancer was told.) Shinchosha. Tokyo, Japan
- Nishimura, T. et al. 2006. “seimei rinri kenkyukai no katsudo hokoku: inochi ni okeru Identity no shiza.” (“A Report of the Bioethics Study Group activities: Care of Life from the Viewpoint of Identity.”) *St. Luke’s College of Nursing Journal*. 32, 3. pp. 20 – 27.
- Nishizawa, M. 2005. “Songenshi to Jikoketteiken.” (“Dying with Dignity and Autonomy.”) *Nanbyo to Zaitaku Care*. 11(5): 20 – 24.
- Nomura, T. et al. 2005. “Gan kokuchi wo uketa Kanja shinri kara Kangoshi no Kakawari wo Saiko suru.” (“Re-thinking the role of nurses through the psychology of the patients whose cancer already told.”) *The 36<sup>th</sup> Nihon Kango Gakkai Ronbunshu*. Nihon Kango Kyokai. pp. 484 – 486.
- Novack, D. et al. 1979. “Changes in Physicians’ Attitudes Toward Telling the Cancer Patient.” *JAMA*. Vol. 241, 9: 897 – 900.
- Novack, D. et al. 1989. “Physicians’ Attitudes Toward Using Deception to Resolve Difficult Ethical Problems.” *JAMA*. Vol. 261, 20: 2980 – 2985.
- Ogawa, M. (ed./wtn.) 2002. *Shinjitsu wo Tsutae Sasaeru tameno Gan Kokuchi no Tebiki.* (Manual on Telling Truth of Cancer: for Truth told and Help provided.) Shinko Koeki Isho Shuppanbu. Tokyo, Japan
- Ogawa, T. and Paku, Y. 2006. “Makki Gan Kanja no Kazoku ni taisuru Kokuchi.” (“Truth-telling to the Family of the Terminal Cancer Patient.”) *Byoin*. Vol. 65. No. 9. pp. 744 (58) – 747 (61).
- Ogawa, Y. 2008. *Iryo Rinrigaku.* (Medical Ethics.) Hokuju Shuppan. Tokyo, Japan
- Oken, D. 1961. “What to Tell Cancer Patients: A Study of Medical Attitudes.” *JAMA*. Vol. 175, 13: 1120 – 1128.
- Okuda, J. et al. 2007. *Fuhensei to Tayosei.* (Universality and Diversity.) Sophia University Press. Tokyo, Japan
- Olick, R. 2000. “Disclosing genetic information to family members: Do old paradigms fit the new medicine?” *New Jersey Medicine*. January: 43 – 46.
- Olin, H. 1972. “A Proposed Model To Teach Medical Students The Care of the Dying Patient.” *Journal of Medical Education*. Vol. 47: 564 – 567.
- Ooi, G. 1989, Heisei Gan-nen. *Shumatsuki Iryo.* (Medical Practice of End of Life.) Kobundo. Tokyo, Japan

- Osler, W. 1899. *The Principles and Practice of Medicine. Designed for the Use of Practitioners and Students of Medicine. Third Edition.* D. Appleton and Company. New York, USA
- Paterson, I. 1994. "Consent to Treatment: Somebody's Moved the Goalposts." *Clinical Oncology*. Vol. 6: 179 – 182.
- Peabody, F. 1928. *The Care of the Patient*. Harvard University Press. Cambridge, Massachusetta, USA.
- Pellegrino, E. and Thomasma, D. 1993. *The Virtues in Medical Practice*. Oxford University Press. New York, USA
- Peppercorn, J. et al. 2008. "Self-Reported Practices and Attitudes of US Oncologists Regarding Off-Protocol Therapy." *Journal of Clinical Oncology*. Vol. 26, 36: 5994 – 6000.
- Peteet, J. et al. 2013. "Spirituality and Religion in Oncology." *A Cancer Journal for Clinicians*. pp. 280 – 289. American Cancer Society, USA.
- Piatt, L. 1946. "The Physician and the Cancer Patient." *Ohio State Medical Journal*. 42: 371 – 372.
- Platt, R. 1947. "The Practice of Medicine." *The Lancet*. August 30: 305 – 307.
- Porter, R. 1993. "Thomas Gisborne: Physicians, Christians and Gentlemen." In Wear, A. et al. (ed.) 1993. *Doctors and Ethics: the Earlier Historical Setting of Professional Ethics*. Rodopi B.V., Amsterdam. pp. 252 – 273.
- Powell, M. and Anesaki, M. 1990. *Health Care in Japan*. Routledge, London, UK
- Powell, T. 2006. "Culture and Communication: Medical Disclosure in Japan and the U.S." *The American Journal of Bioethics*. 6(1): 18 – 20.
- Radovsky, S. 1985. "Occasional Notes: Bearing the News." *The New England Journal of Medicine*. Vol. 313, 9: 586 – 588.
- Randall, F. and Downie, R. 1996. *Palliative Care Ethics: A Good Companion*. Oxford University Press. Oxford, UK
- Rothenberg, L. et al. 1996. "The Relationship of Clinical and Legal Perspectives Regarding Medical Treatment Decision-Making in Four Cultures." *Annual Review of Law and Ethics*. 4: 335 – 379.
- Rothman, D. 1980. *Conscience and Convenience*. Little, Brown and Company. Boston, USA
- Rothman, D. 2000. "The Shame of Medical Research." *The New York Review of Books*. 30 November, 2000: 60 – 64.
- Royce, J. 1995. *The Philosophy of Loyalty*. Vanderbilt University Press. Nashville, USA



- Ruhnke, G. et al. 2000. "Ethical Decision Making and Patient Autonomy: A comparison of Physicians and Patients in Japan and the United States." *CHEST*. 118: 1172 – 1182.
- Ryan, C. et al. 1995. "Becoming none but tradesmen: lies, deception and psychotic patients." *Journal of Medical Ethics*. Vol. 21: 72 – 76.
- Ryan, P. 2005. "Approaching Death: A Phenomenologic Study of Five Older Adults with Advanced Cancer." *Oncology Nursing Forum*. Vol. 32, No. 6. pp. 1101 – 1108.
- Sachs, B. 1942. "Be An Optimist." *Journal Mount Sinai Hospital*. 8: 323 – 325.
- Samp, R. and Curreri, A. 1957. "A Questionnaire Survey on Public Cancer Education obtained from Cancer Patients and Their Families." *CANCER*. Vol. 10. 382 – 384.
- Saunders, C. et al. (ed.) 1981. *Hospice: the living idea*. Edward Arnold. London, UK
- Saunders, C. (ed.) 1990. *Hospice and Palliative Care an interdisciplinary approach*. Edward Arnold. London, UK
- Saunders, C. and Baines, M. 1989. *Living with Dying: The management of terminal disease*. Oxford University Press. Oxford, UK
- Sawyer, D, et al. 1993. "Canadian physicians and euthanasia: 2. Definitions and distinctions." *Can Med Assoc J*. 148(9): 1463 – 1466.
- Sayers, G. et al. 2001. "The value of taking an 'ethics history'." *Journal of Medical Ethics*. Vol. 27: 114 – 117.
- Seelig, M. 1943. "Should the cancer victim be told the truth?" *Journal Missouri M. A*. Vol. 40, 2: 33 – 35.
- Seikatsu Joho Center. 2006. "Heikin Jumyo." ("Life Expectancy.") *Nihon no Jinko Tokei Soran. (Total data of Japanese Population.)* Tokyo, Japan
- Sekimoto, M. et al. 2004. "Patients' preferences for involvement in treatment decision making in Japan." *BMC Family Practice*. 5:1.
- Sekine, T. 2007. *Iryo rinri no Keibu: kanja no omoiyaru senjin no chie. (Japanese history of Medical Ethics: wisdom tradition to take good care of patients.)* Hokuju Shuppan. Tokyo, Japan
- Seo, M. et al. 2000. "Telling the diagnosis to cancer patients in Japan: attitude and perception of patients, physicians and nurses." *Palliative Medicine*. 14: 105 – 110.
- Sepulveda, C. et al. 2002. "Palliative Care: The World Health Organization's Global Perspective." *Journal of Pain and Symptom Management*. Vol. 24. No. 2. August: 91 – 96.
- Shibusawa, H. et al. 2008. "Shumatsuki Kanja no Yogo Kokuchi ni taisuru Rikai wo Jirei kara manabu." ("Learning from the terminal patient's situation of how telling prognosis is understood.") *Kitakanto Med J*. No. 58. pp. 246 – 247.

- Shimazaki, T. 1952, Showa 27<sup>th</sup> year. *Kanjo no Sekai. (The World of Feeling.)* Iwanami Shoten. Tokyo, Japan
- Shimizu, T. 1997. *Iryo Genba ni nozomu Tetsugaku. (Philosophy for Medical Practice.)* Keiso Shobo. Tokyo, Japan
- Shimizu, T. 2000. *Iryo Genba ni nozomu Tetsugaku II. (Philosophy for Medical Practice II.)* Keiso Shobo. Tokyo, Japan
- Shoji, M. et al. 2005. “terminal ki ni aru gan kaja no spiritual care no shiten.” (“A Perspective of Spiritual Care for the cancer patients at end-of-life.”) *Seijin Kango. II, the 36.* pp. 18 – 20.
- Skilbeck, J. et al. 2005. “An exploration of family carers’ experience of respite services in one specialist palliative care unit.” *Palliative Medicine.* 19(8): 610 – 618.
- Slote, M. 2001. *Morals from Motives.* Oxford University Press. Oxford, UK
- Solomon, H. 1947. “Psychiatric Implications of Cancer.” *Rocky Mountain Medical Journal.* Vol. 44: 801 – 804.
- Sperry, W. 1951. *The Ethical Basis of Medical Practice.* Cassell and Company Ltd. London, UK
- Steinhauser, K. et al. 2000. “Factors Considered Important at the End of Life by Patients, Family, Physicians, and Other Care Providers.” *JAMA.* Vol. 284, 19: 2476 – 2482.
- Stohr, K. 2006. “Manners, Morals, and Practical Wisdom.” In Chappell, T. (ed.) 2006. *Values and Virtues: Aristotelianism in Contemporary Ethics.* Oxford University Press. New York, USA. pp. 189f.
- SUPPORT Principal Investigators. 1995. “A Controlled Trial to Improve Care for Seriously ill Hospitalized Patients: The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT).” *JAMA.* Vol. 274, 20: 1591 – 1598.
- Surbone, A. 2006. “Telling the truth to patients with cancer: what is the truth?” *THE LANCET Oncology.* Vol. 7, Issue 11, 944 – 950.
- Swanson, J. and Cooper, A. 2005. *A Physician’s Guide to Coping with Death and Dying.* McGill-Queen’s University Press. Montreal, Canada
- Takeo, K. et al. 1991. “Health Workers’ Attitudes Toward Euthanasia in Japan.” *Int. Nurs. Rev.* 38(2): 45 – 48.
- Tamura, C. 2006. “The Family-Facilitated Approach Could Be Dangerous If There Is Pressure by Family Dynamics.” *The American Journal of Bioethics.* 6(1): 16 – 18.
- Tanida, N. 1994. “Japanese Attitudes towards Truth Disclosure in Cancer.” *Scand J Soc Med.* Vol. 22, No. 1: 50 – 57.

- Tanida, N. 2003. "Kanja e warui shirase wo tsutaeru tokino Do's & Don'ts!" ("How to tell Bad News to Patients: recommended strategies.") *Chiryō. Zokan-go*. Vol. 85. pp. 080 (680) – 083 (683).
- Tanikawa, T. 1958, Showa 33<sup>rd</sup> year. *Higashi to Nishi tonō Aida no Nihon: heiwateki kyoōzon eno michi. (Japan in between the East and the West: the way of peaceful co-existence.)* Iwanami Shoten. Tokyo, Japan
- Tanimura, C. et al. 2004. "Makki gan kanja eno Gan Kokuchi wo kyōhi shita Kazoku no Taiken." ("Qualitative Research on Families with Terminal Care Cancer Patients: The Experience of Families who Refuse Truth-Telling.") *Nichi Gan Kan Kaishi*. Vol. 18, No. 2. pp. 38 – 46.
- Tattersall, M. 2010. "Truth telling and consent." In Hanks, G. et al. (ed.) 2010. *Oxford Textbook of Palliative Medicine. Fourth Edition*. Oxford University Press: 290 – 295.
- Taylor, C. 1991. *The Ethics of Authenticity*. Harvard University Press. Cambridge, Massachusetts, USA
- Teramoto, M. 1985, Showa 60<sup>th</sup> year. *Kango no nakano Shi. (Death, while taking care of patients.)* Nihon Kango Kyokai Shuppankai. Tokyo, Japan
- Terasawa, Y. et al. 2003. "byōmei kokuchi sareta gan kanja ni taisuru kangoshi no kotoba-kake no tokucho." ("The Characteristics of the nurses' utterances to the patients whose cancer already told.") *Shi no Rinsō*. 26, 2. p. 195.
- Thomasma, D. 1994. "Telling the Truth to Patients: A Clinical Ethics Exploration." *Cambridge Quarterly of Healthcare Ethics*. Vol. 3: 375 – 382.
- Thomsen, O. et al. 1993. "What do gastroenterologists in Europe tell cancer patients?" *The Lancet*. Vol. 341, Feb. 20: 473 – 476.
- Tobin, G. and Begley, C. 2008. "Receiving Bad News." *Cancer Nursing*. Vol. 31, No. 5, E31 – E39.
- Tokei Suri Kenkyūjo. 1992, Heisei 4<sup>th</sup> year. *Nihon-jin no Kokuminsei. Sengo. Showa-ki, Sosbu. (The Characteristics of Japanese people. After World War II, Showa era, total data.)* Idemitsu Shoten. Tokyo, Japan
- Tokuda, Y. et al. 2004. "Evaluation of end of life care in cancer patients at a teaching hospital in Japan." *Journal of Medical Ethics*. 30: 264 – 267.
- Tokunaga, S. 1982. *Shi no nakano emi. (Laughter around Death.)* Yumiru Shuppan, Tokyo, Japan
- Travaline, J. et al. 2005. "Patient-Physician Communication: Why and How." *JAOA*. Vol. 105. No. 1. January: 13 – 18.
- Tsuboi, K. 2004. "shinko gan kara shi ni itatta kanja oyobi kazoku e no iryōsha no kakawari." ("How a physician dealt with a patient who died of advanced cancer and his family.") *The Nursing Journal of Hiroshima International University*. Vol. 2:19 – 25.

- Tsuchida, T. 2008. “Shi ni tsuite no Jiko-Kettei towa.” (“Thinking of Making Decision of one’s own Death.”) In Kimura, R. et al. 2008. *Inochi no Bioethics: kankyō, kodomo, seishi no ketsudan. (The Bioethics of Life: environment, children, and decisions of life & death.)* Corona Publishing Co. Ltd. Tokyo, Japan. pp. 108f.
- Tuckett, A. 2004. “Truth-telling in Clinical Practice and the Arguments For and Against: A Review of the Literature.” *Nursing Ethics*. Vol. 11, 5: 500 – 513.
- Ueda, S. 1997. *Nishida Kitaro: ningen no shogaito iukoto. (Nishida Kitaro: the life of human being.)* Iwanami Shoten. Tokyo, Japan
- Underwood, F. 1949. “Early Cancer Is Curable.” *Mississippi Doctor*. Vol. 26: 280 – 281.
- Valadier, P. 2003. “The Person who Lacks Dignity.” In Ammicht-Quinn, R. et al. (ed.) 2003. *The Discourse of Human Dignity*. Concilium. SCM Press. London, UK. pp. 49f.
- Vincent, J. 1998. “Information in the ICU: are we being honest with our patients? The results of a European questionnaire.” *Intensive Care Med*. Vol. 24: 1251 – 1256.
- Watsuji, T. 1991. *Fudo: ningen-gaku teki kosatsu. (The Influence of Nature: Investigation for the study of human being.)* Iwanami Shoten. Tokyo, Japan
- Wear, A. 1993. “Medical Ethics in Early Modern England.” In Wear, A. et al. (ed.) 1993. *Doctors and Ethics: the Earlier Historical Setting of Professional Ethics*. Rodopi B.V., Amsterdam. pp. 98 – 130.
- Weeks, J. et al. 1998. “Relationship Between Cancer Patients’ Predictions of Prognosis and Their Treatment Preferences.” *JAMA*. Vol. 279, 21: 1709 – 1714.
- Westberg, D. 1994. *Right Practical Reason: Aristotle, Action, and Prudence in Aquinas*. Oxford University Press. New York, USA
- White, A. et al. 2008. “The Attitudes and Experiences of Trainees Regarding Disclosing Medical Errors to Patients.” *Academic Medicine*. Vol. 83, 3: 250 – 256.
- Wittenberg-Lyles, E. et al. 2008. “Communicating a terminal prognosis in a palliative care setting: Deficiencies in current communication training protocols.” *Social Science & Medicine*. 66: 2356 – 2365.
- Yamamoto, K. 1981, Showa 56<sup>th</sup> year. *Inochi to Katachi: Nihon-bi no Minamoto wo saguru. (Life and Form: searching for the Origin of the Beauty of Japan.)* Shinchosha. Tokyo, Japan
- Yamazaki, F. 1996. *Byoin de Shinuto iukoto. (Meaning to die in Hospital: For patients, nurses, doctors and all other people.)* Bungei Shunju. Tokyo, Japan
- Yamazaki, T. 2006, Heisei 18<sup>th</sup> year. “Shi ni itaru madeno katei wo ikinuku shinko haigan kanja to kazoku no jittai to kango shien ni kansuru kenkyu.” (“A Research on the Lived Experiences of the Patients with Advanced Lung Cancer and Their Families.”) *Ochanomizu Igaku Zasshi*. 54, 3. Tokyo, Japan. pp. 79 – 99.

- Yedidia, M. and MacGregor, B. 2001. "Confronting the Prospect of Dying: Reports of Terminally Ill Patients." *Journal of Pain and Symptom Management*. Vol. 22. No. 4. pp. 807 – 819.
- Yomiuri Newspaper, 2006. *Truth-telling Statistics of Japan on Withholding and/or Withdrawing life-prolonging equipments / treatment*. the 31<sup>st</sup> of July, 2006. Tokyo, Japan
- Yomiuri Newspaper, 2008. *Truth-telling Statistics of Japan on Withholding and/or Withdrawing life-prolonging equipments / treatment*. the 26<sup>th</sup> of July, 2008. Tokyo, Japan
- Yoshida, S. 2000. *Taminal Kea-no Bamen. (The Real cases of Terminal Care.) Kango to Kaunseringu II. (Nursing Care and Counselling II.)* Medica Shuppan. Osaka, Japan
- Young, G. 1981. "Hospice and health care." In Saunders, C. et al. (ed.) 1981. *Hospice: the living idea*. Edward Arnold. London, UK. pp. 1 – 3.
- Zockler, C. 1989. "Guidance of the severely ill patient following detailed information about his disease." (German) *Wiener Medizinische Wochenschrift*. 139(21): 502 – 504.