

# Handling Cancer: Ethical Discussions about Cancer in Japan

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## Contents

Introduction	2
1. Cancer in Japan: The factual background	2
1.1 Cancer incidence and mortality	2
1.2 Cancer and money	3
1.3 Lifestyle and cancer	3
2. Ethical problems and suggestions	4
2.1 Voices of discontent	4
2.2 Rising health costs: highlighting individual responsibility, creating a health-conducive environment:	5
2.3 Paternalism, patient protection and patient responsibility	6
3. Informing about Cancer Diagnosis: Short History of a Discourse	7
3.1 Initial discourse: Disclosure of Cancer - yes or no?	7
Motifs of non-disclosure	8
Case dismissed: embracing change	8
3.2 Negotiating truth: The NCC “Manual on disclosing cancer diagnosis”	9
3.3 Truth in practice	10
3.4 Summary	11
3. Concluding Remarks	12
References Cited	13

## Introduction

Cancer is one of the major causes of death in affluent industrialised societies, and Japan is no exception to that rule. In spite of ever more effective therapies, cancer still causes concern and anxiety for various reasons. The afflicted individuals fear a painful and still often gruesome fate. Medical institutions have to answer to the needs of patients who wish for hope as well as increasingly request information and state-of-the-art therapies. Social security systems have to cope with rising costs and social policy has to provide equitable access to medical treatment and to answer questions of distribution of burdens. A host of ethical questions is involved in all these challenges.

The following brief sketch of ethical discussions about cancer in Japan cannot attempt to give a full picture of the issues at hand. Instead, the paper tries to give some information on the factual background of cancer in Japan, followed by an ad-hoc overview of ethical topics currently discussed in relation to cancer. The question of whether or not, and if, how, to inform patients of a diagnosis of cancer has been especially widely discussed in Japan, and will be treated in a more detailed fashion. The concluding remarks enumerate various points of contention – with the intention of elucidating problems and misconceptions rather than offering solutions.

## 1. Cancer in Japan: The factual background

### 1.1 Cancer incidence and mortality

According to figures compiled by the Ministry of Health, Labour and Welfare and published by the National Cancer Center, in Japan 320.315 people died from cancer in 2004. That amounts to 253.9 cancer-related deaths in 100.000 people, and to 31.1% of all deaths (total number: 1.029.952). (Ministry of Health, Labour and Welfare 2005b)

Of all lethal cancers, most common in males are lung cancer (22.3%), followed by stomach cancer (17.2%); most common in females are abdominal (colorectal) cancer (14.6%), followed by stomach cancer (14.2%) and lung cancer (12.3%). All in all, we see less stomach cancer and uterus cancer than in previous years.

(Ministry of Health, Labour and Welfare 2005c)

A combined analysis of various figures presented by the Ministry of Health, Labour and Welfare reveals that while cancer incidence and mortality are rising in total, the age-adjusted rate of cancer mortality is slowly declining. The ratio of deaths per cancer incidence is also declining. Especially we find less stomach cancer, which is in addition more successfully treated. (Ministry of Health, Labour and Welfare 2005a, 2005b and 2005c)

In sum, among the roughly 1 million Japanese that die every year, 320.000 die from cancer. Lung, stomach and abdomen (colorectal tracts) are the most prominent sites of lethal cancer. While cancer incidence is rising, age adjusted cancer mortality is slowly decreasing. Cancer thus remains a major cause of anxiety, but is no longer a hopeless diagnosis.

## 1.2 Cancer and money

Total health costs were listed by the Ministry of Health, Labour and Welfare as amounting to roughly 24.4 trillion Yen (167 billion EUR) in 2001, rising to roughly 29.6 trillion Yen (206.2 billion EUR) in 2004. In 2001, 2.2 trillion Yen (15.33 billion EUR), or 9.04% of all estimated medical expenditures, were cancer related. Overall health costs, public health spending, and cancer-related expenditures tended to rise considerably over the past years, with the latter multiplying nominally by factor 5.85 between 1977 and 2001, and annual growth rates of public health spending between 3.8% and 7.6% in 2001-2004. (Kôsei rôdô shô 2006, fig. 1-1, 1-2; Ministry of Health, Labour and Welfare 2005d) While health costs increase, cancer-related costs and public medical expenditure increase more sharply.

(NB: All numbers given in this paragraph are estimates and meant only to give a rough idea of the financial dimensions involved. The Ministry of Health, Labour and Welfare quotes different figures in different statistics.)

## 1.3 Lifestyle and cancer

From statistics of potentially cancer-related habits given by the National Cancer Center (Ministry of Health, Labour and Welfare 2005e), it can be inferred that proportionally less people smoke a greater sum total of cigarettes. The proportion

of male adults smoking has decreased much more dramatically (from 82.3% in 1965 to 56.9% in 2004) than in the case of women, but continues to hover on a much higher level. Alcohol consumption per capita has risen, as has the absolute number of heavy drinkers. In general, the Japanese eat a less energy-rich diet that contains proportionally more protein and fat and less carbohydrates than 40 years ago.

The NCC establishes a correlation of these consumption habits to the prevalence of certain kinds of cancer. Most importantly, tobacco consumption is deemed responsible for the high rate of lung cancer incidence. Kawara Naohito (2003: 178) lists traffic and industrial exhausts as additional causes for lung cancer, a salt-rich diet as being responsible for stomach cancer, and fat and high-calory food as related to breast and colon cancer. However, there are no officially acknowledged data on environmental influences on cancer incidence. German and European data indicate less influence on cancer than often assumed, but e.g. dioxin exposure in Japan has been persistently higher than in Europe.

To sum up, tobacco is an important factor in the incidence of lung cancer, one of the major causes of death. Changing dietary habits are presumed to relate to the decrease of stomach cancer and the increase of abdominal cancer. No data assessing environmental influences such as industrial or traffic exhausts are given by the NCC or the Ministry of Health, Labour and Welfare.

## 2. Ethical problems and suggestions

### 2.1 Voices of discontent

Concerning ethical problems discussed in relation to cancer therapy in Japan, the NHK program “Questioning Cancer Therapy in Japan”, aired on Jan. 7, 2006 opens a window on various grievances.

A major problem that found mention in the program was one of justice: Huge differences in the quality of treatment seem to exist depending on the area the afflicted live in. Patients in rural areas find it particularly difficult to get good medical treatment. The NHK program made mention of “cancer refugees” traveling far to get appropriate medical care.

Another point of contention was a perceived conflict of interest between the

health administration and afflicted individuals. The promotion of “public health”, a cause dear to concerned officials, does not necessarily translate into “best individual care”, and public vs. individual well-being can in many cases be pinpointed against each other.

An NHK mailing list dedicated to the support of cancer patients ([http://www.nhk.or.jp/support/board/00006/00006\\_1888.html](http://www.nhk.or.jp/support/board/00006/00006_1888.html)) reveals further grievances, especially in relation to the distribution of burdens. A lack of clarity concerning costs and cost distribution is repeatedly mentioned. (Eg. [http://www.nhk.or.jp/support/board/00027/00027\\_1884.html](http://www.nhk.or.jp/support/board/00027/00027_1884.html)) Due to the vicissitudes of the insurance system, treatment in a small hospital that outsources tests may be more expensive for the patient, adding to the regional inequalities in treatment quality. ([http://www.nhk.or.jp/support/board/00027/00027\\_2402.html](http://www.nhk.or.jp/support/board/00027/00027_2402.html)).

An “Action Plan” published by the Ministry of Health, Labour and Welfare in 2005 notes an “uneasiness” (*fuan*) concerning the existing system. The main aim of the plan itself is to create an integrated system of response that provides for high quality information, treatment, and support to all patients throughout the country. (Kôsei rôdô shô 2005, literal quote from p. 1)

A long-standing discussion has dealt with various problems surrounding the communication of a cancer diagnosis. Informed consent procedures, which have become at least technically the standard in Japan, have sometimes been criticized by patients in the following respect:

- explanations are too technical and general
- lack of emotional support
- some wish for more encouragement. (National Cancer Center 1996, topic 2.4)

A closer analysis of this particular discussion will be given below.

## **2.2 Rising health costs: highlighting individual responsibility, creating a health-conducive environment:**

Public health officials currently emphasize that a large portion of the continually rising health costs are related to issues of life-style. Promotion of health consciousness and health-enhancing patterns of consumption and habitual action is seen as an important factor in increasing the population’s health and keeping health-related costs at a tolerable level. Concurrently, the “Law on Health

Promotion”, promulgated in 2005, in Art 1, § 2 recognizes a “duty” of Japanese citizens to:

- increase awareness of and understand the relationship between lifestyle and health
- act in a way becoming to their health.

However, no enforcement of these duties seems to be envisioned so far. Subsequent sections of the law focus on measures like creating a smoke-free environment in public areas, and on quality and composition of food in canteens and other institutions that provide food for a larger number of regular customers. (See Law on Health Promotion, e.g. §§ 20, 25)

Similarly, the Ministry of Health, Labour and Welfare’s 2005 Action plan against Cancer emphasizes encouragement of non-smoking and the proliferation of information on lifestyles that prevent cancer. The same ministry’s initiative “Healthy Japan 21” equally seeks to heighten awareness of healthy lifestyle through the cooperation of various public and private institutions. (<http://www.kenkounippon21.gr.jp/>; see also [http://www.dietitian.or.jp/english/jda\\_newsletter/healthy\\_people\\_in\\_japan21.html](http://www.dietitian.or.jp/english/jda_newsletter/healthy_people_in_japan21.html) for a summary)

### **2.3 Paternalism, patient protection and patient responsibility**

Arguably, the single most discussed cluster of ethical problems concerns questions of how to best protect patients’ interests and dignity in individual treatment. Apart from conflicts between public, institutional and private interests, a fundamental conflict has often been perceived between patient protection and patient responsibility. More specifically, paternalistic patterns of behaviour have been legitimized by the aim of emotionally protecting the patient from overbearing demands on his decision-making faculty in a critical situation. This discussion will be explored in greater detail in the following section.

### 3. Informing about Cancer Diagnosis: Short History of a Discourse

#### 3.1 Initial discourse: Disclosure of Cancer - yes or no?

While procedures of informed consent are part and parcel of the legal framework of medicine in Japan since the 1960s, there has been much contention about the question whether patients should be informed in full about a diagnosis of cancer. Some major stages of this dispute shall be elucidated below.

Firstly, in 1983 the Ministry of Health and Welfare set up a council to deliberate various bioethical questions. Among the council's members were Hanaoka Keiji, then president of the Japan Medical Association, Suzuki Eiji, director, Mitsubishi Chemicals, the renowned historian of ideas Nakamura Hajime, the sociologist Nakane Chie (well-known for her book on "Human relationships in a vertical society"), and the famous manga author Tezuka Osamu. The council strove to assess the status quo, and to evaluate the pros and cons of "disclosing cancer."

Concerning the state of affairs, they found that 42%-62% of doctors would disclose diagnosis of cancer in the incipient stage. The rate depended on the attending physicians field of specialization and status. Internists showed a lower disposition to disclose the diagnosis than surgeons. Privately operating doctors displayed a wider margin of opinion than those working in hospitals.

Concerning a diagnosis of cancer in the terminal stage, only 18-29% of all physicians questioned opted for even partial disclosure. The council noted that these findings were similar to the figures found in the USA in 1961. However, by 1979, disclosure had become a standard practice, adhered to by 97% of all doctors. (Kôseishô kenkô seisakukyoku ijika 1985: 161)

No comprehensive data concerning the wishes of Japanese patients were available at the time; however, the council quoted American data suggesting that 85% of those questioned said they wished to be informed even of a fatal diagnosis. A study on Japanese patients by Ôhara Kenjiro confirmed this picture, showing that more Japanese than expected wished to be informed even of a fatal diagnosis. (Kôseishô kenkô seisakukyoku ijika 1985: 162)

### Motifs of non-disclosure

Investigating further, the council pondered the following motives operating in the (then still standard) procedure of avoiding disclosure:

1. In spite of growing success in cancer therapies, such a diagnosis would still often be perceived as a ‘death mark’: Patients thus might easily lose all hope of being cured, and give up on themselves.
2. The shock of learning about a cancer diagnosis might negatively affect the patient.
3. Specific mention is made of the feeling of loneliness that may overcome patients as they feel singled out by their affliction. These feelings may be exacerbated by the importance Japanese society places on group conformity, a point specifically emphasized by sociologist Nakane Chie. *Kôseishô kenkô seisakukyoku ijika* 1985: 169)
4. Doctors may be motivated by a misunderstanding about the patient’s wishes. They tend to assume that patients want to retain their peace of mind, even though the patient is eager to be informed.
5. Hierarchical thinking, which places the attending physician above the patient, precludes a “duty to report” on the doctors’ side as well as a “right to know” on the patients’ side.
6. Families (esp. wives) equally strive to protect their afflicted relative’s peace of mind. The principle of “amae” (indulgent dependency) is invoked to explain this attitude. (*Kôseishô kenkô seisakukyoku ijika* 1985: 168-9)
7. A cultural preference for indirect communication precludes especially explicit confrontation with unpleasant truths. Concomitantly, as Nakamura Hajime pointed out, Buddhism as one of the major moral traditions in Japan has, in its Japanese form, endorsed benevolent lies as a legitimate means of salvation. (*Kôseishô kenkô seisakukyoku ijika* 1985: 164)

### Case dismissed: embracing change

However, the council found only limited validity in such reasoning against

disclosure. It saw transition toward a general practice of reporting the truth to the patient as a path Japan was already taking and should pursue further.

The main reasons given in favour of full disclosure were:

1. While withholding the truth from the patient may prevent the kind of shock caused by confrontation with an inauspicious diagnosis, patients may still suspect something is seriously wrong. The alleged peace of mind of the patient kept ignorant about his disease may in truth be an ambiguous state of uncertainty at best.
2. In a society where information on medical matters is becoming more and more easily accessible, withholding the truth will often not even be a realistic option.
3. In the light of a widening array of therapies, cooperation by the patient is growing more and more essential.

Thus, after due deliberation the council commended a soft response: While the truth should not be forced on patients, it said, doctors should be ready to inform. Depending on the situation, indirect means of communication should be considered. The council also suggested that patients be questioned about their general attitudes when accepted into a hospital, in order to be able to choose a path of communication in accordance with their preferences. (Kôseishô kenkô seisakukyoku ijika 1985: 171)

### 3.2 Negotiating truth: The NCC “Manual on disclosing cancer diagnosis”

At least in terms of official policies, the situation in Japan quickly moved beyond the soft, volitional approach recommended by the Ministry of Welfare’s Council in 1983, and toward disclosure as a standard procedure. This can clearly be seen by the National Cancer Center’s “Manual on Disclosing Cancer Diagnosis” (Gan kokuchi manyûaru), drafted in 1996 and still in circulation. (Quoted as “Manual” below). The Manual’s initial paragraph states:

Concerning the question of disclosure, the discussion, especially in hospitals specializing on cancer treatment, has presently moved beyond the question of “whether or not to disclose”. The time has arrived to ask, rather, “How do we communicate the facts, and how do we respond to the patient and

support him or her afterwards? (NCC 1996: 1, Transl. CS)

Accordingly, the rest of the manual elaborates chiefly on proper precautions and procedures in disclosing a diagnosis that is bound to disconcert the patient.

Basic rules, as set forth in the Manual, are:

1. Diagnosis will be communicated to the patient directly, and to his relatives only later.
2. Communication of the diagnosis shall be realized in a manner supportive of the patient's abilities to cope with the disconcerting truth. Specifically, the Manual mentions that
3. One attending physician shall be responsible for the patient and accompany him through all stages of diagnosis and treatment.
4. The diagnosis shall be communicated in person, and in a private atmosphere that allows the patient to exhibit his feelings without being embarrassed.
5. The attending physician shall offer to see the patient again later the same day, or at least to talk to him over the phone.
6. The patient will always be told the truth. However, careful language will be used to avoid unnecessary shock. Gradual information during the various stages of diagnostic procedures is recommended as a way to avoid shock.
7. The patient will not be left alone to cope with the truth. The attending physician and nurses will be ready to communicate with him about his situation and further steps in therapy. The Manual specifically mentions that emotional communication may be easier with nurses.
8. Disclosing information adequately and supporting the patient afterwards is described as an essential professional skill of a medical expert.

### 3.3 Truth in practice

While the Manual describes standard procedures in hospitals specializing in cancer therapy, the general situation is still characterized by a greater variety of practices. While earlier arguments against a duty to perform often had a paternalistic air, there are at least some cases where a course of not explicitly informing the patient about the diagnosis is taken in accordance with his known

preferences.

A Japanese nurse quoted in an article in the journal "Nursing Ethics" (2001) describes such a situation in which a patient did NOT want to discuss her terminal diagnosis:

She had said clearly she didn't want to know she had cancer ... so nobody told her. Then she was talking about her disease but she used another name. The physician had used that other diagnosis to explain her symptoms. And she was talking like "it's a pretty serious thing. Could be feeling like death" and so on. I didn't realize it but my tone didn't change and she didn't change either. A usual conversation was going on. ... She had bone metastasis and, when she didn't move, she was okay, but when she moved she had great pain. She loved golfing. So she was talking about golf, saying, "If this is cured then I want to go golfing but maybe I cannot golf any more." ... My friend, who was observing us, said that usually in such a situation, the other person will say, "No, that's not true. You can be well and you can golf again. After you cure this disease you can go golfing." That's the usual reaction. But I said, "Well, it may not be. After you have a bone disease it's hard to play sports." For me it's not a special thing. She is talking about golf, why not talk about golf? We don't need to talk other things or guess from her words. We can see behind the words. (Doutrich et al. 2001: 453)

However, the same report mentions that many Japanese doctors still refuse to treat the patient as an equal, who has a right to be informed and make choices about his treatment.

### 3.4 Summary

Initial resistance against disclosure of diagnosis was partly couched in terms of Japanese culture; needs of the patients were often misrepresented because of a lack of data. Official policy has moved toward full and explicit disclosure, with concomitant support for the patient. Experience in specialized hospitals has emphasized the importance of nurses in communicating about the disease.

In the clinical world, a variety of practices persist. Specialized hospitals take a cooperative approach and see informing their patients while providing for proper

support and counseling as the path of best practice. Many doctors outside specialized cancer centers still take a paternalistic attitude, which may be just one part of an effort to protect themselves. On the other hand, indirect communication is sometimes used by nurses according to the patients' wishes, and in response to their needs. The variety in attitudes thus may in part be due to persisting differences of qualification and equipment among Japanese hospitals catering to cancer patients.

### 3. Concluding Remarks

Only selected aspects of ethical questions concerning cancer prevention, cancer treatment and interacting with cancer patients could be treated in this short paper. However, some general remarks may be extrapolated from our findings.

1. While ethical differences are often expected to exist between countries with different dominant religious traditions, our analysis has shown few traits in the Japanese discussion that can be interpreted as "specifically Japanese". While paternalistic attitudes among doctors are sometimes legitimized with reference to idiosyncrasies of Japanese culture and tradition, the medical system in Japan as a whole follows the trajectory from paternalism to cooperation seen in other industrial societies. However, traditions of indirect, implicit communication may have helped to conceive of ways to work with patients refuting explicit discussion of their diagnosis or treatment.
2. A major problem in relation to cancer treatment appears to be one of distributive justice. Due to structural inequalities between different regions in Japan, patients do not receive the same quality of treatment. New measures envisioned by the government are trying to address this issue, which figures as a major in the "Action Plan" formulated in 2005.
3. In the light of rising health costs, public health policy is pressed to emphasize preemption and prevention. New legislation states an individual duty to lead a "healthy life", while attempting to regulate social and environmental factors contributing to cancer incidence. A conflict between individual liberties and

public health clearly exists, but is rarely explicitly expressed.

4. In addition, educational material by the National Cancer Center and the Ministry of Health, Labour and Welfare regularly understates the factor age in cancer epidemiology. The factor of costs for therapies is rarely openly discussed. Considering the demographics of an ageing society, one major issue appears to be the unwillingness of Japanese society and Japanese politicians (shared by other affluent, and ageing, industrialized societies) to openly discuss uncomfortable truths – including the fact that even the best social and medical system cannot prevent death and disease as the eventual fate of any individual. On the contrary, exaggerated expectations in medical technology and its accessibility may undermine the foundations of a society based on individual freedom – a problem recently discussed by the Japanese bioethicist Morioka Masahiro in his book on “painless civilization”. (Morioka 2003)

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