

Disclosure preferences regarding cancer diagnosis and prognosis: to tell or not to tell?

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Telling people that they have cancer has a great impact on their lives, so many doctors are concerned about how they should inform patients about a cancer diagnosis and its prognosis. We conducted a general population survey in Japan to investigate people's preferences on receiving this information. There were no significant differences in respondents' preferences according to the seriousness of the cancer. Full disclosure of the diagnosis was preferred by 86.1% of the respondents, while 2.7% wanted non-disclosure. As for the initial provision of information, the majority preferred partial disclosure concerning the prospects of complete recovery (64.5%) and the expected length of survival (64.1%). Those who responded negatively to the statement, "If I am close to the end of my life, I want to be informed of the fact so I can choose my own way of life", were more likely to want non-disclosure on diagnosis. The results suggest that, 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. Contrary to popular belief, the seriousness of the cancer and people's demographic characteristics displayed little impact in this study.

Cancer has a great impact on patients' lives, so the extent to which physicians should inform them of the diagnosis and prognosis poses a difficult decision in clinical settings. An increasing number of people experience this problem because cancer ranks as the third most common cause of death worldwide, accounting for approximately 12% of all recorded deaths.¹ In many cultures around the world, a cancer diagnosis is not routinely disclosed to patients. Previous studies show that physicians in some countries routinely withhold a diagnosis of cancer from their patients.^{2–7} Even in the USA, where doctors have to inform patients of a cancer diagnosis, they still have the problem regarding prognosis information.⁸

In Japan, physicians have gradually been informing patients of cancer diagnoses since the early 1990s.^{9–10} In many cases, however, prognosis information is still concealed from them, especially if the condition is incurable.^{11–12} Although some physicians provide full information from the outset, others give none, not even regarding diagnosis.¹² Although Japan's National Cancer Center has compiled a set of guidelines for cancer disclosure, each hospital has a different policy.¹³ No laws or regulations stipulate that doctors must obtain informed consent from patients. In this context, we need to develop a more consistent policy on cancer disclosure.

The patient, the family, and the doctor are the main players in cancer disclosure. According to legal precedents in Japan, doctors are given a wide range of discretionary powers regarding disclosure.^{14–16} As a rationale for these discretionary powers, doctors report various reasons such as protecting patients from psychological distress caused by disclosure of the diagnosis, families' wishes for non-disclosure to patients, and the fact that most patients themselves do not wish to be told the truth.^{13–17} However, it is reported that there is no relationship between cancer disclosure and mental harm.^{18–20} It is more often family members than patients who do not want doctors to tell the truth to patients,^{10–21} so patients' needs for information often remain unsatisfied in Japan, where many doctors tell family members first, not the patients. Doctors' discretionary powers and families' powers

of attorney need to be reconsidered in the light of patients' preferences.

Although a number of authors have already reported studies on patients' preferences regarding cancer disclosure, many of them asked about overall preferences concerning disclosure, not specifically distinguishing between cancer diagnosis and prognosis.^{22–24} Most researchers have considered patients' characteristics only in order to predict their preferences, although many doctors believe that these preferences are influenced by the seriousness of the cancer and patients' attitudes toward medical care.^{13–19} The first purpose of the present study was to examine patients' preferences regarding the disclosure of a cancer diagnosis and its prognosis separately. The second purpose was to examine the most important factors related to disclosure preferences, taking account of details such as patient characteristics, the seriousness of the cancer, and patients' attitudes towards medical care.

METHODS

This study was a cross-sectional, stratified random sample survey of the general population (in their 20s to 50s) in Japan. Participants were selected from eligible voters in 'A' ward in the Tokyo Metropolitan Area. We chose 'A' ward as being representative of Tokyo because various social indices such as the proportion of elderly people, the average length of education undertaken, the population growth rate, and the industrial structure were consistent with the Tokyo average.²⁵

We mailed a questionnaire to 990 people in October 2002. The sample size was calculated to provide adequate power to detect differences among disclosure preferences. We received responses from 427 people (43.1%). It usually took less than 20 minutes to complete the questionnaire. Ten respondents were excluded from the analysis because of incomplete data. Thirty-one (7.4%) had had experience of being told about a cancer diagnosis by their doctors. There were no significant differences in responses between those who obtained cancer

Abbreviations: CR, complete recovery; LS, length of survival; STAI, State-Trait Anxiety Inventory

Table 1 Details of the five scenarios

Scenario	Length of survival (months)	Prospect of complete recovery	Effective therapy	Response rate (%)
1	12	Present	Present	43.4
2	6	Present	Present	44.4
3	6	Absent	Present	42.1
4	6	Absent	Absent	42.1
5	1	Absent	Absent	41.0

disclosure and those who did not, so we included the 31 respondents in the analysis.

The questionnaire presented a hypothetical scenario to each respondent, and asked “How would you want to be told, if you were in such a situation?” We created five versions of the scenario, one of which was randomly allocated to each questionnaire. Each scenario commenced with identical words: “From laboratory results, a doctor found you had cancer X, but you don’t know yet.” The five scenarios varied according to the seriousness of the cancer, as shown in table 1: expected length of survival without treatment, prospects of complete recovery, and presence or absence of effective therapy. There were no significant differences in the response rate among the five scenarios.

The questionnaire also asked respondents about their attitudes toward medical care: “If I am close to the end of my life, I want to be informed of the fact so I can choose my own way of life.” “If I have no chance of recovery, I do not wish to be told about this fact so that I do not lose hope of recovery.” “As it is hard to receive all of the bad news at the same time, I would like to be told little by little.” We included these items because they could be used as an interview sheet or as part of a doctor’s questionnaire to predict patients’ preferences in actual clinical settings.

After presentation of the scenario, the respondents were asked about their preferences on diagnosis and prognosis disclosure. The choices for disclosure preferences on diagnosis were:

1. I would not want to be given any information regarding my diagnosis (non-disclosure).
2. I would like to obtain information regarding my diagnosis of a general nature but not in detail (partial disclosure).
3. I would like to be given all information regarding my diagnosis (full disclosure).

Choices for disclosure on the prospect of complete recovery (CR) and expected length of survival (LS) were:

1. I would not want to be given any information about the prospects of CR (LS) (non-disclosure).
2. I would like to obtain information on the prospects of CR (LS) of a general nature but not in detail (partial disclosure).
3. I would like to be told about my prospects of CR (LS) eventually. However, I would like to receive only general information on the prospects of CR (LS) when I am initially informed about the disease (full gradual disclosure).
4. I would like to be told about my prospects of CR (LS) without delay (full disclosure without delay).

Akabayashi *et al*⁶ indicated that many Japanese people were accustomed to and commonly preferred ambiguity, so we included partial disclosure in these choices.

The questionnaire items also included the Japanese version of the State-Trait Anxiety Inventory (STAI), which assesses predisposition to anxiety and approaches the construct from trait and state perspectives.^{27, 28} The Japanese version of STAI is standardised and widely used. In the present study we used the trait part of STAI (Cronbach’s $\alpha = 0.90$ in the present sample).

We described the distributions of the disclosure preferences about diagnosis, CR and LS. The Kruskal-Wallis test was used to determine the preference differences among the scenarios. We used logistic regression analysis to distinguish people who preferred non-disclosure of diagnosis and prognosis (no information group) from others, and used a stepwise procedure to identify covariates strongly associated with the responses. We controlled the differences in the scenarios by including them as dummy variables in the equation. To reduce the number of variables for the logistic regression analysis, we entered variables that remained significant ($p < 0.10$) by bivariate analysis. To distinguish people who preferred full disclosure of the diagnosis and prognosis without delay (all information without delay group) from others, we also used logistic regression analysis, as set out above. Statistical analyses were conducted using SPSS Version 11.0J.

RESULTS

Table 2 shows the characteristics of the 417 respondents. Their mean age was 41.8 ± 10.6 years, 57.3% were women, and 32.6% had graduated from college. There were no significant differences in the characteristics of the respondents among the five scenarios.

There were no significant differences in respondents’ disclosure preferences among the five scenarios regarding diagnosis ($\chi^2 = 6.48$, $df = 4$, $p = 0.17$), CR ($\chi^2 = 5.17$, $df = 4$, $p = 0.27$), or LS ($\chi^2 = 3.67$, $df = 4$, $p = 0.45$). We therefore combined the data for all scenario groups. The distribution of the respondents’ disclosure preferences for diagnosis and prognosis is shown in figure 1.

Regarding diagnosis, most respondents (86.1%) wanted full disclosure. For prognosis (CR and LS), partial disclosure was most frequently chosen. There were no significant differences in respondents’ disclosure preferences according

Table 2 Characteristics of the respondents

Characteristic	Mean (SD)	No. (%)
Age (years)	41.8 (10.6)	
STAI (total score)	42.3 (9.8)	
Female sex		239 (57.3)
College graduate		136 (32.6)
Living alone		60 (14.4)
Married		261 (62.7)
Living with adult child		85 (20.4)
Living with infant child		151 (36.2)
Breadwinner		198 (47.5)
Not religious		326 (78.2)

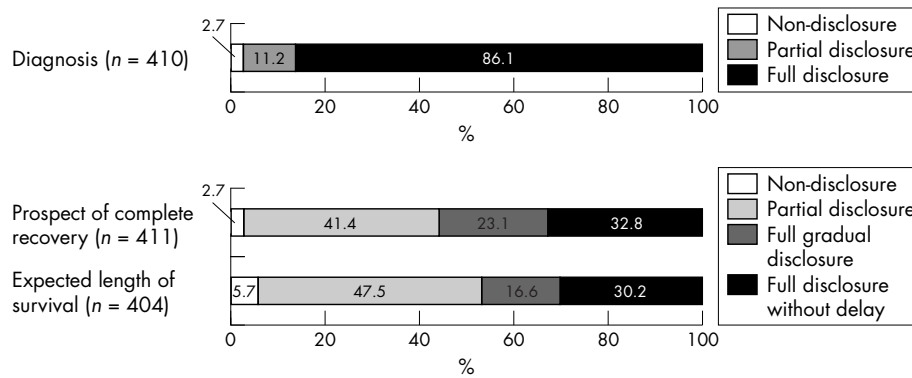


Figure 1 Respondents' disclosure preferences for diagnosis and prognosis.

to age, sex, STAI score, educational background, and living arrangements.

We present odds ratios (OR) and 95% confidence intervals (CI) for significant covariates by logistic regression analysis (tables 3 and 4). Respondents who disagreed with the statement, "If I am close to the end of my life, I would like to be informed of the fact so I can choose my own way of life" (OR = 38.7, 95% CI 2.70 to 556) and those who were neutral to the same question (OR = 17.6, 95% CI 1.18 to 262) were more likely to want non-disclosure. Those who disagreed with, "As it is hard to receive all of the bad news at the same time, I would like to be told little by little" were more likely to want full disclosure on both the prospects of CR and the expected LS without delay (OR = 4.90, 95% CI 2.54 to 9.40). Those who disagreed with, "If I have no chance of recovery, I do not wish to be told about the fact so as not to lose hope of recovery" (OR = 5.31, 95% CI 1.91 to 14.80), and those who were not married (OR = 2.37, 95% CI 1.41 to 4.00) were also more likely to want full disclosure without delay on both the prospects of CR and the expected LS.

DISCUSSION

This study revealed some notable findings. Regarding the seriousness of cancer, there were no significant differences in respondents' preferences about diagnosis and prognosis disclosure among the five scenarios. Furthermore, there was little difference even between scenario 1 and scenario 5, the two extremes of the seriousness of cancer. Thus, although many doctors in Japan consider the seriousness of cancer when determining their attitude towards providing full information,^{13, 19} it was not a factor in this study and had little impact on the logistic regression analyses. It may therefore be unwise to give priority to the seriousness of the cancer.

On combining the data from all the scenario groups, the distribution of disclosure preferences was approximately

Table 4 Logistic regression analysis of wanting to be told bad news gradually or not at all† (n = 404)

	OR	95% CI
As it is hard to receive all of the bad news at the same time, I would like to be told gradually		
Agree	-	-
Neutral	1.36	0.58 to 3.25
Disagree	4.90**	2.54 to 9.40
If I have no chance of recovery I do not wish to be told, so as not to lose hope of recovery		
Agree	-	-
Neutral	0.91	0.23 to 3.59
Disagree	5.31**	1.91 to 14.80
Unmarried	2.37**	1.41 to 4.00

**p < 0.01.
 †Nagelkerke R² = 0.337.
 -, no numerical data presented.

Table 3 Logistic regression analysis of attitude to receiving information† (n = 404)

	OR	95% CI
If I am close to the end of my life, I want to be informed of the fact so I can choose my own way of life		
Agree	-	-
Neutral	17.6*	1.18 to 262
Disagree	38.7**	2.70 to 556

*p = 0.05; **p = 0.01.
 †Nagelkerke R² = 0.457.
 -, no numerical data presented.

consistent with previous studies. The distribution of respondents' overall disclosure preferences is shown in figure 1. The proportion of respondents who wanted no information regarding cancer disclosure (2.7%) is consistent not only with a large-scale Japanese survey,⁹ but also with an investigation carried out in the UK.²⁸ It is also consistent with an investigation conducted on American hospitalised patients.⁸ Nearly half of these respondents preferred full disclosure of the prognosis at some time during clinical treatment. Although doctors' methods of providing cancer disclosure differ, patients' preferences may therefore be consistent across countries.

The respondents displayed different attitudes towards disclosure of the diagnosis, the prospects of CR and the expected LS: 86.1% wanted full disclosure of the diagnosis, however 55.9% (gradual full disclosure 23.1% + full disclosure without delay 32.8%) of respondents wanted full disclosure of the prospects of CR and 46.8% (gradual full disclosure 16.6% + full disclosure without delay 30.2%) wanted full disclosure of the expected LS. The distribution of each preference was widely different, so medical professionals should not assume that patients who want full disclosure of a diagnosis automatically also want full disclosure without delay on the prospects of CR and the expected LS. It is important properly to evaluate patients' preferences regarding prognosis disclosure.

We considered it an important finding that the majority of respondents wanted gradual or partial disclosure of the prospects for a CR (64.5%: partial disclosure 41.4% + gradual full disclosure 23.1%) and the expected LS (64.1%: partial

disclosure 47.5% + gradual full disclosure 16.6%) on the initial occasion of providing information. In clinical practice, medical professionals have to consider to what extent they tell patients about diagnosis and prognosis at this time. The results suggest that a disclosure policy of providing patients with full information on diagnosis and part information on prognosis could satisfy the preferences of most patients.

We have to avoid providing information to patients who do not really want it, as well as giving too little information to those who especially want more. A disclosure policy such as "To provide patients with full information about their diagnosis and general information about their prognosis when providing information for the first time" would not necessarily meet the preferences of all patients. In a clinical setting, we must deal with patients who do not want any information about diagnosis and prognosis and also with those who want full disclosure without delay. In many cases, we do not know which patient has which preference. To date, no evidence has been found regarding the risks to patients when those not wishing to receive information are provided with full information against their will, and vice versa. We distinguished these two groups from the others in an effort to respect the preferences of both of them.

Patients' attitudes towards medical care were more important than patient characteristics and the seriousness of the cancer in the no information and all information without delay groups. Examining the characteristics of these two groups showed that particular items of respondents' attitudes towards medical care were significant factors in both analyses. In predicting respondents' disclosure preferences, their attitudes towards specific aspects of medical care ("If I have no chance of recovery, I don't want to be told about the fact so as not to lose hope of recovery." "If I am close to the end of my life, I want to be informed of the fact so I can choose my own way of life.") were more effective than more general items ("I want to determine my own way of life, even if I am a cancer patient." "I have to put my affairs in order to avoid causing any trouble after my death."). Physicians may be able effectively to distinguish the no information and all information without delay groups from others by providing these particular answer choices in advance.

This study also revealed notable findings on the various factors that influence respondents' disclosure preferences. Although several studies have shown that age, educational background, and trait anxiety were significantly associated with patients' disclosure preferences,^{23-24, 28} these items had no impact in this study. Patient characteristics may have minimum impact on patients' preferences. As only marital status was significantly associated with the all information without delay group, it was suggested that having no one to turn to increased participants' awareness of self-determination.

We excluded respondents who wanted only partial disclosure about diagnosis (11.2%) from the no information group. Although some previous studies have assumed that people who wanted partial disclosure about diagnosis would not want to be given information on prognosis,²⁴ all of our respondents who wanted partial disclosure about diagnosis also wanted partial or full disclosure about prognosis. Giving them no information or providing them with a false diagnosis is contrary to respecting the wishes of these people.

This study has several limitations. Although the response rate was moderate for a general population survey, we still have to consider that the characteristics of the respondents may not be wholly representative of the general population. We restricted the participants to adult inhabitants of an urban area in Japan, so further study is required to test the validity of these findings. However, the proportion of

respondents who wanted no information regarding cancer diagnosis is similar to those reported in the large-scale surveys that included older adults.^{9, 26} We therefore believe that these limitations do not significantly affect the overall outcome of our study. To simulate the actual situation of cancer disclosure we used specific scenarios about the seriousness of cancer. As a result, there was no difference between respondents who experienced cancer disclosure as a patient and those who did not, and the prognosis preferences revealed are consistent with a previous study on patients.²⁹ These findings suggest that the method used succeeded in simulating a real situation.

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