

# *Prevalence and determinants of diagnostic and prognostic disclosure by radiotherapists and surgeons to patients with terminal cancer in Hong Kong*

R. Fielding, L. Ko, L. Wong, A. J. Hedley, M. L. M. Gilhooly and F. S. H. Tam

## **Abstract**

This paper identifies the prevalence and determinants of diagnostic and prognostic information given to terminally ill cancer patients in Hong Kong. Surgeons and radiotherapists (n = 153) were interviewed about the information they gave to their most recently deceased cancer patients. This was explored in relation to doctors' and patients' demographic data, diagnosis, the stage of disease at disclosure, and doctors' attitude. Diagnostic information was disclosed partially in 68% and fully in 46% of cases. Prognosis was disclosed partially in 38% and fully in less than 10% of cases. Determinants of diagnostic disclosure included doctors' attitudes about death, and perceived responsibility for disclosure. The doctor's training and work, and the patient's request for information determined the level of disclosure. After adjustment for a number of social and demographic factors, only the patient's education level remained a significant determinant of the level of prognostic disclosure. A significant proportion of terminally-ill cancer patients do not engage in discussion of diagnosis or prognosis with the doctor caring for them during the last stages of their disease. This reflects the unwillingness to discuss such matters, giving a low priority to information provision, paternalism or other factors, such as little importance being attached to such topics at the late stage of cancer. Thus many cancer patients may fail to learn important information about their disease if they have not engaged in discussion of these topics earlier in their illness. The results of this paper have important implications for medical education in caring for patients with cancer.

*Keywords:* Cancer; Disclosure; Diagnosis; Prognosis; Information

## **Introduction**

Effective communications in cancer care are important therapeutically and may have profound effects on the disease course.<sup>1-6</sup> Yet professional attention to the communication needs of cancer patients varies

substantially.<sup>7-12</sup> Studies consistently indicate that, while the majority of Western cancer patients want access to all their medical information, irrespective of its nature,<sup>13-16</sup> many physicians still fail to provide the information that patients desire or need.<sup>17-19</sup> Physicians often erroneously believe that patients do not want to know, or that someone else has informed the patient.<sup>13</sup> Withholding information may reflect attempts to protect patients from distressing emotions, but the practitioner is unable to give support to the patient while withholding important information the patient desires.<sup>20</sup>

It is unclear what discriminates patients who want information (~ 90%) from those who do not.<sup>16</sup> Few studies reported on information disclosed by practitioners in non-anglophone cultures. The objectives of this study were: (1) to identify the prevalence and important determinants of diagnostic and prognostic disclosure in malignant disease, and (2) to explore the

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extent of, and the strategies used during such disclosure, among a sample of Chinese medical practitioners in Hong Kong.

## Methods

Of Hong Kong's population of nearly six million people, more than 94% are of Chinese origin. Most suspected cancer cases are referred to medical, surgical or radiotherapy specialists who, on confirming diagnosis, take over the long term management of the patient. Hence, they are the practitioners usually informing the patients about their disease.

### *Sampling criteria*

After consulting a wide range of sources, including the Department of Health, the College of General Practitioners and a number of surgeons and oncologists, to gauge the pattern of referral and management of cancer patients across the territory, it was decided that all hospitals in Hong Kong that had surgery and/or radiotherapy departments with more than 19 beds would be targeted for study. Data collection took place before the establishment of the Hospital Authority, and at that time there were six government regional, 14 subvented, and six private hospitals satisfying this criterion. These were stratified by total surgical/radiotherapy bed numbers and invited to participate in the study.

### *Government and subvented hospitals*

Four hospitals had surgical/radiotherapy units exceeding 300 beds, eight had 101 to 300 bed units, and nine had units of up to 100 beds. Each department at each hospital agreeing to participate was asked to provide a list of all available doctors. This revealed a range of existing doctor-bed ratios. Based on the doctor-bed ratios identified from these lists, we sampled between 64 to 92% of eligible doctors in each unit to adjust for the variation in staffing levels. Six hospitals were excluded: one provided end-stage care only and the other five were serviced by external doctors, many from units already targeted.

### *Private hospitals*

The proportion of private doctors based on the ratio of private to government/subvented surgical/radiotherapy beds in the hospitals sampled was calculated ( $496/3025 = 16.4\%$ ). Thus, 16% of the sample were recruited from amongst private doctors. Five private hospitals were approached and asked to provide names of radiotherapists/surgeons with admission rights to their hospitals.

Once the hospital had given its agreement to allow its staff to be interviewed, letter and telephone contacts to individual department or team heads were followed by visits to confirm participation and staff name lists, and, in private hospitals, name lists of doctors with admission rights. All subjects were randomly selected from these name lists. Where the proportion of subjects recruited from a unit fell below 70% of the intended number, replacements were selected from the same unit, and failing that, other units of comparable size. The eligibility criterion for inclusion was that the doctors must be currently working in the department/unit/team as a clinician.

### *Data collection*

Each doctor was interviewed about the diagnostic and prognostic information given by him to his most recently deceased patient with cancer.<sup>6</sup> This method avoids selection bias of favourable patients by the doctor. It also avoids doctors reporting what they think they should do rather than what they actually do. To minimize recall bias, the patient was required to have died within the past three months.

A three-part, semi-structured interview was used. Part 1 focused on doctors' demographic and professional details, including training and working situation. Part 2 documented patient demographics, diagnostic and disclosure information, and Part 3 explored doctors' cultural beliefs, attitudes towards death, and disclosure practices. All these areas were probed further with supplementary questions. The interview, of 30 to 40 minutes duration, was piloted five times to ensure it was comprehensive and to train the two interviewers to achieve inter-rater reliability above 0.9. Further details of the interview schedule are available from the first author upon request.

### *Data coding & analysis*

#### Diagnosis and stage of disease

Doctors were asked to classify the patient's disease type (ICD-90<sup>21</sup>) and stage (TNM,<sup>22</sup> Ann Arbor or Duke disease stage) when diagnosis was first given. Doctors not giving an established staging were asked to classify the stage of disease in one of the four categories: early, mid, late or terminal disease.

While we recognize that both diagnosis and prognosis can be defined either broadly or narrowly and may vary considerably both between doctors and even between different patients of the same doctor, the nature of the analysis planned required that we adopt a consistent definition of a diagnosis and prognosis. Only after data had been collected and keyed into computer could we construct the coding categories

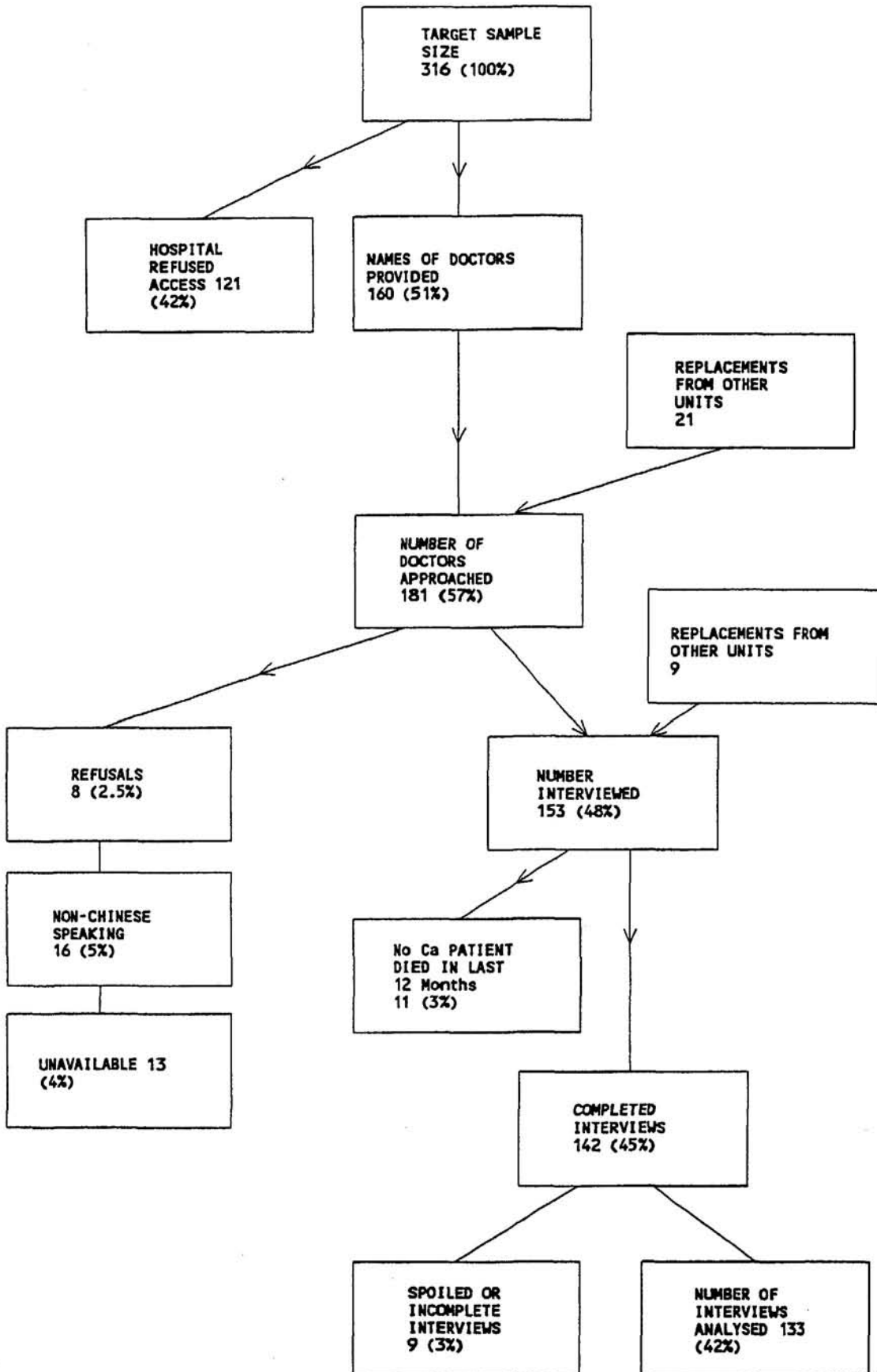


Fig. 1. Sampling strategy.

for diagnosis and prognosis based on (1) the nature of the responses we obtained at interview, and (2) consideration of advice based on both the clinical experience of the team members and a further eight other practicing doctors. It is important to note that participants interviewed were asked if they gave a diagnosis/prognosis to their most recently deceased cancer patient. Those doctors answering affirmatively were asked to say what information constituted this diagnosis/prognosis. The criteria for coding diagnosis and prognosis were based on this information given by the participants and not pre-defined by the researchers. Thus we adopted a tight operationalization of both diagnosis and prognosis as set out below on the grounds that these constituted the principle elements of diagnostic or prognostic discussions involving the participating subjects.

#### Coding diagnostic disclosure

Doctors were asked if they gave a diagnosis, and if so what information they disclosed. Criteria used to define the extent of diagnosis disclosed included: mention or not of a disease name, a statement of its nature (malignant), and discussion of signs and symptoms. Coding was then given according to the criteria in Table 1.

#### Coding prognostic disclosure

Doctors were asked whether a prognosis was given and if so what information was disclosed. A vague or specific discussion of disease course, discussion of the incurable nature of the disease, and discussion of expected duration of remaining life, or a statement about anticipated outcome defined level of prognostic disclosure. Coding was then given according to the criteria in Table 1.

The data were subject to bivariate analyses to test for goodness of fit. Logistic regression was used to control common variance and identify predictors of disclosure. All analyses used SPSS-PC+. Data are reported with 95% confidence limits (95%CL) for point estimates. Odds ratios (OR) illustrate the probability of disclosure associated with particular variables.

## Results

### 1. Sample

Of the 20 hospitals approached, two subvented, four small private hospitals and one teaching hospital surgical unit refused participation; two government surgical units in different hospitals failed to respond to repeated requests. In all, refusals and non-responses at the unit or hospital level excluded 121/316 poten-

tial subjects (42%). Only 160 subjects were made available. Including the 21 replacement doctors, 181 subjects were approached: 16 were non-Chinese speaking, eight refused to participate, and 13 were unavailable (e.g. emigrated). Nine more replacements were then obtained. In all 153/181 (84%) doctors were interviewed. Eleven had administrative roles not meeting our inclusion criterion (despite being on the staff list, they had no or few patient care responsibilities. There were nine unusable interviews leaving 133 valid cases for analysis (see Fig. 1).

#### Characteristics of doctors

Doctors' ages ranged from less than 30 years (36%), 30 to 39 years (41%), to greater than 40 years (21%). Nine (7%) were female. All but one were Chinese raised in Hong Kong (90%) or other Southeast Asian countries (10%). Only 34% professed some religious belief, almost all Christian.

Medical education was received in Hong Kong (79%), Indochina (7%), or elsewhere (12%) and 57% held a postgraduate qualification. All described themselves either as surgeons (79%) or radiotherapists, employed in general hospital (87%) (of whom 18% were employed in a teaching hospital), or general (5%), special (5%), or mixed (1.5%) clinics. Government employed 65% at medical officer (71%) or senior medical officer/lecturer (24%) grades, while a small number (4%) held consultant, associate or full professorial posts. The remainder worked in subvented (22%) or private settings (13%). In all, 42% had less than five years medical experience, 25% between five to nine years experience, 22% 10 to 19 years experience, and 11% over 19 years experience.

#### Cancer patients

Males (84) outnumbered female (49) patients. Ages ranged between 14 to 93 years; 72% were over 50 years and 12% less than 40 years old. All were Hong Kong Chinese with primary (38%), secondary (21%), college (8%), or unknown (32%) educational levels. Occupational roles included professional or managerial (14%), clerical, sales or service (4%), manual (17%), housewives (22%), and other occupations (3%); a further 13% were unemployed and 3% retired. The occupations of the remaining 23% were unknown. In 45% of the cases, patients were known to have no (37%), or some (8%) religious beliefs. Patients were married (75%), single (11%) or no longer married 10%.

The primary tumor was located in digestive organs in 37% and in intrathoracic organs in 37% of the cases, followed by bone or connective tissue structures (7.5%), genitourinary (7.5%), lymphatic systems (4.5%), and oropharynx (4%). The most common di-

**Table 1. Levels of diagnostic and prognostic disclosure to patients and their relatives**

Level of disclosure	Number (%; 95% CL)	
	Patients	Relatives
<b>Diagnostic</b>		
4. Name & Nature & Signs	15 (16%; 9–24%)	25 (24%; 16–32%)
3. Two of the above	47 (52%; 42–61%)	30 (29%; 20–38%)
2. Any one of the above	27 (30%; 21–39%)	44 (43%; 34–52%)
1. None of the above	2 (2%; 0–4%)	5 (5%; 1–9%)
Total	91	104
<b>Prognostic</b>		
5. Specific & incurable & expectancy	1 (2%; 0–6)	1 (1%; 0–3%)
4. Specific & either incurable or expectancy	4 (8%; 0–15%)	6 (6%; 1–11%)
3. Vague & incurable &/or expectancy	10 (20%; 9–31%)	17 (18%; 9–27%)
2. Vague or specific or incurable or expectancy	28 (55%; 41–67)	63 (68%; 59–77%)
1. None of the above	8 (16%; 6–26)	6 (6%; 1–11%)
Total	51	93

agnoses were hepatocellular carcinoma (16.8%), adenocarcinoma of the stomach (16%) and squamous cell or adenocarcinoma of the lung or bronchus (12%).

## 2. Prevalence of disclosure to patients

### Disclosure of diagnosis

Patients received a diagnosis in 91 of the 133 cases (68%; 95% CL 60 to 76%). In 28 cases (21%; 95% CL 13 to 29%), doctors stated they did not reveal a diagnosis. In 12 cases (9%; 95% CL 4 to 14%) patients already knew their diagnosis. Two patients were comatose when the interviewed doctor took over their care.

### Disclosure of prognosis

Patients received a prognosis in 63 cases (48%; 95% CL 40 to 56%). In two cases the patients already knew their prognosis.

## 3. Extent of disclosure to patients

In disclosing diagnosis, 27% of the 91 doctors gave only one kind of information (name or nature or signs and symptoms). Only one in six doctors discussed all three diagnostic components with the patient (Table 1).

Classification of the extent of prognostic disclosure was possible in 51 cases. Only one doctor fully disclosed to his patients specific symptom changes, the incurable nature of the disease and life expectancy while four gave specific information on either life expectancy or the incurable nature of the disease (Table 1). White collar workers and housewives asked for a prognosis more frequently than other groups (Pearson = 16.75, df = 4,  $p < 0.003$ ). Table 2 depicts the frequencies with which different types of information were discussed as diagnosis and prognosis.

The categories used to define diagnosis and prognosis in Table 1 match well with the topics defined by subjects as diagnosis and prognosis given in Table 2.

**Table 2. Different diagnostic and prognostic information discussed with patient: n (%; 95% CL)**

Type of information	Given to patient as	
	diagnosis	prognosis
Name	88 (97%; 94–100%)	5 (8%; 2–14%)
Nature	43 (47%; 36–56%)	3 (5%; 0–10%)
Signs/symptoms	35 (38%; 28–48%)	12 (18%; 9–27%)
Treatment	25 (27%; 18–36%)	4 (22%; 12–32%)
Life expectancy	2 (3%; 0–5%)	20 (31%; 20–42%)
Probable outcome	12 (13%; 6–20%)	21 (33%; 22–44%)
Incurable	11 (12%; 4–19%)	32 (50%; 38–62%)
Pain relief	3 (3%; 0–6%)	8 (12%; 4–20%)
Total (N = 133)	91 (68%; 60–76%)	64 (48%; 40–56%)

**Table 3. Different diagnostic and prognostic information discussed with family: n (%; 95% CL)**

Type of information	Given to family as	
	diagnosis	prognosis
Name	97 (92%; 87–97%)	7 (6%; 2–10%)
Nature	54 (51%; 42–60%)	4 (3%; 0–6%)
Signs/symptoms	45 (43%; 33–53%)	34 (30%; 22–38%)
Treatment	29 (28%; 20–36%)	22 (19%; 12–26%)
Life expectancy	8 (8%; 3–13%)	61 (53%; 44–62%)
Probable outcome	17 (16%; 9–25%)	43 (37%; 28–45%)
Incurable	9 (8%; 3–13%)	37 (32%; 24–40%)
Pain relief only	3 (3%; 0–6%)	7 (6%; 2–9%)
Total (N = 133)	105 (79%; 71–86%)	115 (86%; 81–91%)

This confirms the validity of our definitions of diagnosis and prognosis.

#### 4. Disclosure to family

In contrast to the patient, disclosure of diagnosis to the family was more frequent (Table 3). Most doctors gave the family a diagnosis if they had contact with the family and if the family did not already know (105/115; 92%; 95% CL 87 to 97%). Usually, this information was given at one time (79/105; 75%; 95% CL 67 to 82%), commonly before (29/105; 28%; 95% CL 20 to 36%), at the same time (17/105; 16%; 95% CL 9 to 23%), or after (32/105; 30%; 95% CL 21 to 39%) the patient was told. In 17 cases (16%; 95% CL 9 to 23%) the family was told while the patient was not.

A prognosis was given to the patient's family in 115 cases (Table 3). Frequently, information not given to the patient (41/115; 36%; 95% CL 27 to 45%) was given to the family. When information was given to

the patient, the patient was told first in 26 cases (23%; 95% CL 15 to 31%), and the family first in 23 cases (20%; 13 to 27%). As with diagnosis, prognosis tended to be given at one sitting (82/115; 71%; 95% CL 63 to 79%).

Information to the family focused on the same topics as with the patient; life expectancy, probable outcome and incurable nature of the disease. Less than 10% of families were told the patient would be given palliative care only. In most cases only specific information on the incurable nature of the illness seems to have been given, with vague information given on general expectancy and outcome (Tables 1–3).

#### 5. Determinants of disclosure

Univariate analysis indicated doctors' belief in their responsibility to tell diagnosis reduced the likelihood of diagnosis being withheld, compared to doctors not holding such beliefs (Pearson = 7.41, df = 1,  $p < 0.007$ )

**Table 4. Factors associated with a decision to disclose diagnosis or prognosis directly to patient. (The larger the magnitude of an odds ratio (OR) the lower the likelihood of disclosure)**

Variable	Pearson	df	Significance	OR (95% CL)
<b>Diagnosis</b>				
Doctor's responsibility to tell diagnosis	7.41	1	< 0.007	
Yes				0.5 (0.19–1.16)
No				3.1 (1.6–5.9)
<b>Prognosis</b>				
Place doctor raised	5.74	1	<0.01	
Hong Kong				0.3 (0.1–1.1)
Elsewhere				1.7 (1.3–2.4)
Sub-specialty	3.08	1	<0.08	
Radiotherapy				0.7 (0.5–1.0)
Surgery				1.5 (0.9–2.6)
Patient education	3.55	1	<0.06	
> 10 years				0.7 (0.4–1.0)
< 10 years				1.5 (0.96–2.3)

**Table 5. Variables predictive of level of diagnostic and prognostic disclosure following logistic regression analysis**

Diagnostic variables	$\beta$	S.E.	df	p	R	Exp(B)
Doctor's:						
sub-specialty	2.1	0.93	1	0.031	0.20	7.46
work setting	2.39	0.89	1	0.008	0.28	10.88
not talking death	2.71	1.05	1	0.010	0.26	15.10
good news	-2.05	1.01	1	0.043	-0.18	0.23
constant	-2.63	1.49	1	0.08		
Prognostic variables	$\beta$	S.E.	df	p	R	Exp(B)
Patient age	-1.61	0.90	1	0.07	-0.10	0.20
Doctor's education	1.00	0.49	1	0.04	0.14	2.73
Constant	-0.40	0.30	1	0.18		

$\beta$  = gradient of the slope between the dependent and independent variable;

S.E. = standard error of measurement;

df = degrees of freedom;

p = probability;

R = Regression coefficient;

Exp(B) = exponent of  $\beta$

(Table 4). Doctors holding a postgraduate qualification gave more extensive diagnoses (Pearson = 8.01, df = 3, p = 0.046). Conversely, doctors holding Christian beliefs gave less extensive diagnosis (Pearson = 7.11, df = 2, p < 0.03). No patient variables significantly determined disclosure of diagnosis to either patient or family.

Doctors raised locally more frequently disclosed prognosis compared to doctors raised in other Southeast Asian countries (Pearson = 5.71, df = 1, p < 0.02). Doctor's specialty and patient education approached but did not achieve significance (Table 4). Junior doctors gave more extensive prognostic information than senior doctors (Pearson = 8.27, df = 2, p < 0.02). Patient age (Pearson = 16.42, df = 4, p < 0.03) and marital status (Pearson = 9.86, df = 4, p < 0.05) influenced the level of prognostic disclosure to the family in univariate analysis. Married patients and those aged under 30 years old received more extensive prognostic information.

Using diagnostic disclosure as the dependent variable, doctors' demographic and the following attitudinal variables were used in a logistic regression: doctors' belief that to patients, malignancy implies death, that death implies painful suffering, that Chinese believe it unlucky to discuss death, that the doctor should tell good news only, and that the doctor is responsible for telling the diagnosis.

Four variables significantly predicted diagnostic disclosure. These were doctor's subspecialty (radiotherapists disclosed more than surgeons), type of practice setting (government hospital doctors disclosed more than others), agreeing that Chinese people believe it unlucky to discuss death, and not believing that the doctor should tell good news only (Table 5).

No patient variables predicted diagnostic disclosure.

Using prognostic disclosure as the dependent variable in the logistic analysis, together with the same variables used to explore diagnostic disclosure, only place of medical education significantly predicted prognosis. Overseas educated doctors disclosed less prognostic information. Adding patient variables showed younger patient age and higher educational level to be weakly predictive of greater disclosure (see Table 5).

#### Stage of disease at disclosure

Only 48% (95% CL 40 to 56%) of doctors could not specify their patient's disease stage when they disclosed diagnosis. Full TNM classification was available for 37 cases (41%; 95% CL 31 to 52%), was unclassifiable in 40 cases (30%; 95% CL 22 to 38%), and described as 'not applicable' in 42 cases (32%; 95% CL 24 to 40%). No trend was apparent for disclosure to occur with more advanced disease, but the small numbers prohibit any meaningful analysis.

Diagnosis was disclosed on confirmation (67%; 95% CL 57 to 77%), or before (18%; 95% CL 10 to 26%) or after treatment (7%; 95% CL 2 to 12%). 'Diagnosis' sometimes included prognostic elements: probable outcome in 12 cases (13%; 95% CL 5 to 19%), the incurable nature of the disease in 11 cases (12%; 95% CL 5.5 to 18.5%), and life expectancy in two cases. In 11 cases (8%; 95% CL 4 to 12%), prognosis was given with the diagnosis. Usually prognostic disclosure occurred on disease confirmation (23 cases; 17%; 95% CL 11 to 23%), otherwise usually before (13 cases; 10%; 95% CL 5 to 15%) or after (14 cases; 10%; 95% CL 5 to 15%) treatment. As with diagnosis, doctors had

difficulty defining the disease stage during which prognosis was given and the small numbers again prohibit meaningful analysis.

### 6. Influence of patient requests on disclosure

Did patients' requests for information prompt disclosure? Of those requesting diagnostic information (41/131: 30%; 95% CL 20 to 40%), name (17/41: 41%; 95% CL 26 to 56%), signs and symptoms (16/41: 39%; 95% CL 24 to 54%) and treatment (8/41: 19%; 95% CL 7 to 31%) were most often sought. Outright requests came from 23/41 (56%; 95% CL 41 to 71%), the remainder asking over several occasions. In all but one case doctors provided information when asked.

Prognostic information was requested by 39/131 patients (29%; 95% CL 21 to 38%), primarily on life expectancy. Additional questions addressed treatment alternatives (26%; 95% CL 12 to 40%) and the value of surgery (24%; 95% CL 11 to 37%). Doctors reported providing the information requested in all cases. It therefore seems likely that patient requests for information did influence levels of both prognostic and diagnostic disclosure. Finally, when asked how many patients indicated directly or indirectly they did not want a diagnosis and/or prognosis, only one doctor reported his patient asked not to be told of the prognosis.

## Discussion

Doctors who believed it was their responsibility to tell a diagnosis were six times more likely to do so. The doctor's attitude rather than any patient factors appears to be the principal determinant of diagnosis disclosure. Though doctors' postgraduate training and religious beliefs were significant in univariate analyses, when controlled, neither remained significant. It may be that while postgraduate training better equips doctors for disclosure, religious beliefs tend to inhibit disclosure on compassionate grounds. Similarly, in terms of disclosing a prognosis, univariate analyses suggests that familiarity with the Hong Kong culture influences the decision to give a prognosis. Doctors raised elsewhere may feel less able to judge patients' willingness for such information.

Prevalence and levels of information disclosure reported indicate that a majority of doctors give information to their patients about diagnosis. Over 80% gave information including a name and approximately 40% and 50% gave information on the signs or symptoms and nature of the disease respectively. A prognosis tended to be given less frequently, with less than 50% of patients being given any prognostic information whatsoever. Among these the most common type of prognosis involved mention of the

incurable nature of the illness and less often some mention of probable outcome or life expectancy. Most doctors erred on the side of caution and gave general and somewhat vague information (as defined by themselves) on outcome. This type of information is often the most appropriate when the trajectory of the disease cannot be predicted with certainty.

Compared to a recent U.K. study where 42% of cancer patients were fully aware of their condition and a further 24% were thought to be aware 'at the end', and 15% 'possibly knew',<sup>18</sup> the data reported here do not enable us to assess exactly how many patients knew their diagnosis. While 68% of doctors sampled in the present study claimed to have made some diagnostic disclosure of either the name and/or the nature and/or the signs of their disease, only about 46% discussed specifics. Slightly more than one third of doctors discussed a prognosis with their patient. These levels of disclosure remain low. Significant numbers of patients may not have access to information on which to base major decisions regarding treatment and their remaining life.

Three areas of concern exist consequential upon communications in cancer care: the difficulties in providing quality care for cancer in the absence of open communications between doctor and patient, the consequential risks to the maintenance of ethical standards in cancer care, and, implications for further education and future audit.

Logic dictates that two structural factors determine if patients receive information: the doctor being available and being willing to give information. A doctor who is unavailable cannot be asked for information. One in three patients asked for diagnostic information, which was given. Asking works, and as expected, the more educated the patient, the more likely they were to ask. However, among the remaining 66% of patients who did not ask, only one patient (0.76%) proactively indicated they did not want to be told a diagnosis or prognosis. Two possibly explanations offer themselves for these findings. It may be that less educated patients are less aware of the implications of the information given and they don't ask questions as a result. However, if patients are ignorant of the implications, we must ask why? Studies elsewhere have shown that compared to middle class patients, working class patients have shorter consultation times with doctors and are given less information during those consultations.<sup>23</sup> Explanations offered for these differences include the possibility that doctors perceive working class patients more often bring up inappropriate topics for discussion.<sup>23</sup> Other possibilities are that less educated patients may be more likely perceived as not being able to cope or as being more ignorant of their condition.<sup>24</sup>

The second possible explanation for our data is that it reflects the role of perceived status disparities



between doctor and patient. Uneducated patients are more likely to perceive greater status disparities between doctor and patient. They may therefore feel less confident or articulate and be more unwilling to ask for information, or feel that they will be considered stupid or ignorant if they do question the doctor, though they may still desire the knowledge of a diagnosis and prognosis.<sup>23</sup> These data mirror those reported in other studies of consultation behaviour.

If the patient cannot ask for information (either due to doctor's unavailability or to social inhibition), the doctor's responsibility to take the initiative in giving information becomes crucial. One third of the doctors did not believe it to be their responsibility to give diagnostic information to the patient, a disturbingly high proportion. These were seen, post hoc, to be mostly middle-ranking (senior medical officer/lecturer grade) doctors. Such attitudes do not arise as deference to senior (consultant/senior lecturer/reader/professor) doctors disclosing; non-consultant level doctors disclosed more than senior doctors. Instead, the pattern suggests disclosure becomes less common as medical experience increases. One explanation for these findings is that the more junior doctors spend proportionally greater time on the wards of public hospitals and might be more likely therefore to disclose information.\* It is disturbing if the more senior and experienced doctors do not utilize their considerable clinical expertise to discuss these matters with patients, but leaving the junior doctors to do this. It probably does not matter too much which doctor discloses information to the patient, provided the information given is consistent with that given by other doctors. This often requires a department policy to be defined\* and this can be an important contributor to better information exchange between doctor and patient.

Treatment was discussed by only 20% of doctors and even fewer patients asked about this. In some cases, this did not take place until just before treatment began. Clearly, many patients lack an opportunity to discuss treatment options with their doctor. The benefits to patients from such discussion can be significant in terms of a greater sense of involvement, control and recovery.<sup>11-13,19</sup> This is worrying from the perspective of maintaining ethical standards in medical care.

That junior doctors give more extensive prognostic information may be due to the undergraduate training in Hong Kong in communication skills with seriously ill patients. However, such training may only have a brief effect. Research indicates that, contrary to popular belief, doctors' communication skills do not necessarily improve with time and indeed

may deteriorate with experience. The need for improved communication skills training at all levels of medical education in the territory remains strong. Postgraduate training in communications is more likely to be given to doctors training to become radiotherapists than surgeons. The Academy of Medicine's takeover of postgraduate training in Hong Kong can be influential in encouraging the inclusion of improved communication skills training and psychosocial management of seriously ill patients in membership training.

In one third of the cases only relatives were given a prognosis. When relatives are given information that is withheld from patients, family stress is increased and adequate support for the dying person, both from the family and the doctor, is impaired. This impaired support limits the quality of care that can be provided, separating the patient from those surrounding and caring for him or her, depleting the patient's sense of control, consequently increasing stress, pain and suffering.

#### *Implications for patient management*

There is an important set of pre-requisites needed for adequate information giving. One of these is the availability of privacy for discussion of these matters. Many hospitals do not have available a room which might be used for such purposes. In a public ward, discussion of any matters of this nature without privacy is inappropriate.

It is important to emphasize that with giving prognoses, it is usually inappropriate to state specifically the expected duration of remaining life as the trajectory of a disease is extremely difficult to predict. Though we used a specific statement of expected life as a criteria for the greatest extent of prognostic disclosure, we do not advocate this to be done. Adequate assessment of the patients' information needs is required, which often leads into a discussion of diagnosis. This may or may not lead to a discussion of prognosis. It is important for the doctor to be sensitive to the limits of the patient's capacity for bad news at any one sitting. Disclosure is more easily controlled when done gradually, perhaps over two or three sessions, but sensitivity to the patient's emotional state is required. If disclosure is total, the doctor needs to spend time to help the patient assimilate the information following the disclosure.

A recent U.S. study reporting health care professional's satisfaction with patient involvement in treatment decisions indicated that only about one third of all the medical and surgical attending physicians, house officers and nurses studied were satisfied with (1) the extent to which patients are informed of the different care alternatives, (2) patients' understanding of the information they are told about their condition

\* This interpretation was suggested by one of the reviewers of an earlier draft of this manuscript.

and treatment, (3) patients getting the help they need to make decisions about caring themselves, (4) staff's finding on what critically and terminally ill patients want, (5) the recording of patients' wishes in the medical record, and (6) the discussion by staff on ethical issues in caring for patients.<sup>25</sup> The patient's wishes for the type of end-of-life treatment they wish to have and not have are a highly important component of good care and maintenance of life quality. Treatment preferences cannot be discussed without dealing first with issues of diagnosis and prognosis. Details of the patient's understanding and any preferences for end-of-life treatment (e.g. CPR, ventilation, artificial nutrition/hydration, etc.) should be recorded in the medical record and followed.

Thus, there appears to be a need to encourage more doctors in Hong Kong to make a statement to their patients about their willingness to engage in discussing topics related to the patient's diagnosis, prognosis and care from time to time. In the light of the HA Patient' Charter, which states that the patient has '... the right to be given a clear description of his medical condition, with diagnosis, prognosis, and the treatment proposed, including common risks and alternatives', the data reported herein imply that the majority of patients are not given as much information as is available. This may be because they do not want such information or because they are not offered the opportunity to decide. Only one patient in the present study expressly refused information. There is no reason to believe the silent majority holds similar views. Thus, making a statement of willingness to discuss these issues indicates to the patient the doctor is prepared to enter into such a discussion, if the patient wants to. If, following such a statement, the patient still does not ask questions, the doctor must assume that the patient does not want a discussion at that time. However, the patient's attitude may change and at a later point in time they may wish to have such a discussion. This indicates a need for the doctor to state periodically to the patient his willingness to discuss all and any issues related to the patient's case. There is an onus on the doctor to initiate discussion. The most appropriate way to deal with this is for doctors to let the patient know unequivocally that they have information to give and that they have time for discussion with the patient on his case. There need be no mention of the type of information the doctor has to convey. Yet, to make such a statement is important for the patient, for example, the doctor may say something to the effect of: 'If at any time you want information about your illness, we can talk about that.'

It has been advocated in the U.S. that doctors ask the patient on admission, or on taking over the care of a patient the following: 'Do you wish to be kept informed of important developments in your case?' If

the patient answers negatively, he should then be asked: 'Would you like to nominate a person who can be kept informed on your behalf?' Such a statement at the beginning of a doctor-patient relationship helps the doctor avoid the difficult issue of deciding whether or not the patient wants to know his diagnosis/prognosis. Failure to do so may now be construed by some as unethical. Ideally, this statement should be made regularly, particularly before treatment is initiated, permitting a discussion of options and greater involvement of the patient and his family in decision making.

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