

Letting the cat out of the bag: shifting practices of cancer disclosure in Singapore

Melinda Si Yun [Tan](#)¹, BSc, Kaavya [Narasimhalu](#)¹, PhD, Simon Yew Kuang [Ong](#)^{1,2}, MRCP

INTRODUCTION Communication between patients and physicians is crucial in the disclosure of cancer diagnosis. Although westernisation of Asian societies has resulted in increased awareness of patient autonomy, the family continues to play an important influencing role in the disclosure process. Therefore, in this study, we aimed to characterise the experience of physicians with the disclosure of cancer diagnosis in a westernised Asian population.

METHODS Oncologists at a tertiary hospital were approached to participate in this study. Information pertaining to the extent and approach to disclosure was collated. Logistic regression analysis was performed to characterise factors pertaining to the willingness of physicians to fully disclose a diagnosis of cancer.

RESULTS In all, 25 oncologists (mean age 38 years; 72% men) responded to the survey. A majority of oncologists disclosed a cancer diagnosis directly to the patient over the first few visits. The main reason behind partial or non-disclosure was family objection. Ordinal logistic regression analysis showed that family resistance was the only significant predictor of reluctance to disclose a cancer diagnosis ($p = 0.01$).

CONCLUSION In this pilot study, contrary to previous reports, we found that oncologists were more likely to disclose a diagnosis of cancer to the patient first, that they do not accede fully to the family's request for non-disclosure and that family resistance was the only significant predictor of reluctance to disclose a diagnosis of cancer.

Keywords: Asia, cancer, consent, disclosure, ethics
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INTRODUCTION

Communication between patients and physicians is a complex process that involves understanding the intricacies of the individual patient's background. Patient-physician communication takes on a more important role when disclosing a potentially life-threatening diagnosis such as cancer.⁽¹⁻³⁾ Disclosing a diagnosis of cancer is a difficult balance between respecting patient autonomy and avoiding demoralising the patient.^(1,3-6) In contrast to Western populations where patient autonomy is often perceived as the most important ethical principle, there are additional cultural sensitivities that may affect the disclosure of a cancer diagnosis in Asia.⁽⁷⁻¹⁰⁾

Firstly, in many Asian cultures, a family-centred model of decision making is adopted. Frequently, the diagnosis is first revealed to family members, and subsequent disclosure to the patient occurs only after family consent for disclosure has been obtained.^(11,12) Secondly, doctors and patients in Asia traditionally share a paternalistic relationship governed by the principles of beneficence and non-maleficence, in which the patient often defers his decision to that of the doctor. This has led to physicians underestimating the amount of information that they should disclose to the patient, leaving the patient ill-prepared to make informed decisions.⁽¹³⁾ Finally, as cancer is considered taboo in many Asian contexts, euphemisms such as a growth, lump or mass have been used as a substitute in an effort to keep the balance between open disclosure and preserving hope.^(2,13)

In recent years, there has been an increasing trend toward patient autonomy and full disclosure of cancer diagnosis to the patient in Asia.⁽¹⁴⁾ Several studies have shown that a heightened emphasis on ethics in medical practice has led to a shift from a paternalistic patient-doctor relationship to one in which the patient has more autonomy.^(15,16)

This study was conducted to determine the physician's experience with disclosing a diagnosis of cancer in Singapore. Specifically, we wished to determine the manner in which a diagnosis of cancer is disclosed, the person(s) to whom it is first disclosed, the amount of information that is given away and the factors that influence the disclosure of a cancer diagnosis. The impact of and the physician's reactions to four hypothetical scenarios in which a patient initially has incomplete disclosure of information were ascertained. The results of this study were interpreted in a broader perspective by comparing it with previous studies from Singapore in order to describe the evolution of disclosure practices.

METHODS

Questionnaires were administered to medical, surgical and radiation oncologists from the National Cancer Centre in Singapore. A list of oncologists was obtained from the respective departments, and those with at least one year experience at the institution were approached and interviewed. The study

¹Duke-NUS Graduate Medical School, Singapore, ²Department of Medical Oncology, National Cancer Centre, Singapore

Correspondence: Dr Simon YK Ong, Senior Consultant, Department of Medical Oncology, National Cancer Centre, 11 Hospital Drive, Singapore 169610. drmooyk@nccs.com.sg

was reviewed and approved by the Central Institutional Review Board and informed consent was obtained from all participants.

The interview questionnaire consisted of three sections. The first section obtained information concerning the demographic and professional information of the physician, while the second section obtained information pertaining to the physician's practices in disclosing diagnosis in either percentages or 5-point Likert scales, and the last section obtained the physician's responses to the four case scenarios. The four case scenarios detailed situations in which the patients' families requested the physician to withhold the diagnosis from the patient, with variations in the extent of the patient's disease (resectable vs. metastatic) and point of view (unknown, defers to family, or defers to physician). Physicians were asked for their level of comfort with a family's request for non-disclosure of diagnosis, and a free text response was collected on the reasons behind their responses. The free text responses were collated and are presented below. Physicians were also asked for examples of strategies they found useful in dealing with family collusion. The most popular suggestions are summarised in the discussion.

Ordinal logistic regression analyses were done to establish the factors that determined resistance to complete disclosure of diagnosis. Analyses were performed using STATA 10.0 (StataCorp LP, College Station, TX, USA), and significance was determined with a two-tailed alpha of 0.05.

RESULTS

Of a total of 50 surveys administered, 25 were completed (50%). 16 responders were medical oncologists, five were surgical oncologists and four were radiation oncologists (mean age 38 ± 6 years), who saw an average of 22 ± 19 new cancer patients in a month. The demographics of responders and their preferences in disclosing a cancer diagnosis are summarised in Table I. Briefly, a majority of oncologists (72%) chose to reveal a diagnosis of cancer to the patient before disclosure to the family. A majority of the patients (75%) also received a full disclosure of diagnosis during their first clinic visit (32%) or over the next few visits (48%). The minimum levels of disclosure acceptable by oncologists were varied, with over half preferring full disclosures of diagnosis (52%), and 12% and 24% of physicians preferring the use of euphemisms and partial disclosure for a cancer diagnosis, respectively.

Table II summarises the results of the ordinal logistic regression analysis. In the univariate ordinal logistic regression analysis, family resistance significantly predicted reluctance on the part of the physician to disclose a diagnosis of cancer (odds ratio 3.01, 95% confidence interval 1.27–7.10). There were no other significant predictors of reluctance or willingness for full disclosure. Table III summarises the responses of oncologists to the four hypothetical case scenarios. Regardless of the patient's prognosis, more than half of the oncologists (52%–64%) surveyed were uncomfortable with a family's request for non-disclosure of

Table I. Demographic characteristics and disclosure preferences of responders (n = 25).

Detail	No. (%)
Male gender	18 (72)
Age* (yrs)	38 ± 6
Medical school	
Singapore/Asia	16 (67)
UK/Europe	5 (21)
Others	4 (12)
Designation	
Senior Consultant	7 (28)
Consultant	11 (44)
Registrar	7 (28)
No. of new patients a month*	22 ± 19
Oncologists' preferences in disclosure	
First disclosure to	
Patient	18 (72)
Family	7 (28)
Extent (%) of disclosure received by patient*	
Full	75 ± 21
Partial	28 ± 29
None	7 ± 8
Minimal acceptable disclosure	
Full	13 (52)
Use of euphemisms	3 (12)
Partial	6 (24)
Indirect	2 (8)
None	1 (4)
Timing of first disclosure	
1st possible visit	8 (32)
Over first few visits	12 (48)
When disease progresses	3 (12)
At treatment failure	2 (8)
Reasons behind partial or non-disclosure	
Family's decisions	21 (84)
Physician's opinion	0 (0)
Patient's preference	6 (24)
Patient's impaired comprehension	5 (20)

* Data is presented as mean \pm SD.
UK: United Kingdom; SD: standard deviation

a cancer diagnosis if the patient's preference was unknown. However, if the patient deferred decision-making to the family, then only 24% of oncologists remained uncomfortable. If the patient delegated the decision-making process to the doctor instead, 40% of oncologists remained uncomfortable. When the patient's preference was not known, most oncologists (60%–64%) felt that there would be a negative impact on the patient-doctor relationship. However, if the patient's preference was known, as in scenarios 3 and 4, then most of the oncologists surveyed felt that the impact on the patient-doctor relationship would be neutral (48%–52%) or even positive (16%–20%).

A larger percentage of oncologists (40%) felt that there would be a negative impact on patient-family relationship if the doctor acceded to the family's requests for non-disclosure when the patient's preference was not known, as compared to 12%–24% of oncologists, when patient preference was known. Most oncologists (44%–48%) surveyed felt that there would be a positive impact on the family-doctor relationship if the doctor

Table II. Ordinal logistic regression analysis to determine factors favouring complete disclosure of diagnosis.

Factor	No. (%)			Logistic regression analysis	
	Reluctant/ very reluctant	Neutral	Willing/ very willing	OR (95% CI)	p-value
Age					
Child	12 (48)	9 (36)	4 (16)	0.96 (0.44–2.09)	0.92
Adult	0 (0)	1 (4)	24 (96)	0.42 (0.10–1.70)	0.23
Elderly	1 (4)	1 (4)	23 (92)	1.87 (0.67–5.17)	0.23
Gender					
Male	0 (0)	4 (16)	21 (84)	1.24 (0.43–3.57)	0.70
Female [†]	0 (0)	5 (20)	19 (76)	1.02 (0.37–2.80)	0.97
Ethnicity					
Chinese	0 (0)	5 (20)	20 (80)	1.26 (0.45–3.49)	0.66
Malay	0 (0)	4 (16)	21 (84)	1.56 (0.53–4.58)	0.42
Indian	0 (0)	4 (16)	21 (84)	1.56 (0.53–4.58)	0.42
Caucasian	0 (0)	4 (16)	21 (84)	1.87 (0.64–5.51)	0.25
Religion					
Yes	0 (0)	6 (24)	19 (76)	1.76 (0.67–4.61)	0.25
No	0 (0)	7 (28)	18 (72)	0.38 (-0.54–1.31)	0.41
Marital status					
Single	0 (0)	5 (20)	20 (80)	1.02 (0.37–2.80)	0.97
Married [†]	0 (0)	3 (12)	21 (84)	0.85 (0.27–2.71)	0.79
Education					
None [†]	1 (4)	4 (16)	19 (76)	0.92 (0.38–2.21)	0.86
Primary [†]	0 (0)	5 (20)	19 (76)	1.01 (0.37–2.76)	0.98
Secondary	0 (0)	4 (16)	21 (84)	1.24 (0.43–3.57)	0.70
Tertiary	0 (0)	2 (8)	23 (92)	1.13 (0.31–4.10)	0.85
Comprehension					
Good [†]	0 (0)	1 (4)	24 (96)	0.70 (0.18–2.56)	0.57
Poor	6 (24)	5 (20)	14 (56)	1.15 (0.57–2.33)	0.69
Financial status					
Good	0 (0)	3 (12)	21 (84)	1.23 (0.37–4.04)	0.73
Poor	1 (4)	4 (16)	20 (80)	0.89 (0.36–2.20)	0.79
Breadwinner					
Yes	0 (0)	3 (12)	22 (88)	1.64 (0.49–5.46)	0.42
No	0 (0)	5 (20)	20 (80)	1.02 (0.37–2.80)	0.97
Social support					
Good	0 (0)	2 (8)	23 (92)	0.86 (0.24–3.10)	0.81
Poor	1 (4)	4 (16)	20 (80)	1.04 (0.41–2.64)	0.93
Tumour stage					
Early	0 (0)	2 (8)	23 (92)	0.91 (0.27–3.12)	0.88
Advanced	1 (4)	3 (12)	21 (84)	1.41 (0.57–3.50)	0.45
Prognosis					
Curable	0 (0)	1 (4)	24 (96)	0.38 (0.09–1.60)	0.19
Months	1 (4)	2 (8)	22 (88)	0.94 (0.35–2.52)	0.90
Few years	0 (0)	2 (8)	23 (92)	0.86 (0.23–3.10)	0.81
Many years	0 (0)	2 (8)	23 (92)	1.05 (0.29–3.87)	0.94
Benefits of treatment					
High	0 (0)	1 (4)	24 (96)	0.62 (0.16–2.41)	0.49
Low	1 (4)	2 (8)	22 (88)	1.22 (0.48–3.10)	0.68
Toxicities of treatment					
High	1 (4)	1 (4)	23 (92)	0.92 (0.37–2.32)	0.87
Low	0 (0)	2 (8)	23 (92)	0.86 (0.24–3.10)	0.81
Family resistance					
Present	7 (28)	8 (32)	10 (40)	3.01 (1.27–7.10)	0.01*
Absent	1 (4)	3 (12)	21 (84)	0.51 (0.20–1.33)	0.17

* $p < 0.05$ is statistically significant. [†] Data is missing for one respondent.
OR: odds ratio; CI: confidence interval

acceded to the family's request for non-disclosure. This association was not influenced by the presence or absence of the patient's opinion. Almost all the oncologists would proceed with a form of disclosure (partial disclosure 56%–64%; use of

euphemisms, 24%; full disclosure 0%–8%) despite the family's request for non-disclosure and regardless of the patient's preference. Only 4% of oncologists would choose to accede to the family's request for non-disclosure.

Table III. Oncologists' responses to four hypothetical scenarios.

Variable	No. (%)			
	Scenario 1	Scenario 2	Scenario 3	Scenario 4
Patient's disease	Resectable	Metastatic	Metastatic	Metastatic
Family's request	Not to disclose	Not to disclose	Not to disclose	Not to disclose
Patient's opinion	Unknown	Unknown	Defers to family	Defers to physician
Reaction to request				
Relieved/very relieved	0 (0)	0 (0)*	5 (20)	4 (16)*
Neutral	9 (36)	11 (44)	14 (56)	10 (40)
Uncomfortable/very uncomfortable	16 (64)	13 (52)	6 (24)	10 (40)
Patient-doctor relationship				
Negative	16 (64)*	15 (60)*	8 (32)	7 (28)*
Neutral	8 (32)	9 (36)	12 (48)	13 (52)
Positive	0 (0)	0 (0)	5 (20)	4 (16)
Patient-family relationship				
Negative	10 (40)*	10 (40)*	3 (12)	6 (24)*
Neutral	11 (44)	12 (48)	17 (68)	13 (52)
Positive	3 (12)	2 (8)	5 (20)	5 (20)
Family-doctor relationship				
Negative	7 (28)*	6 (24)*	4 (16)*	4 (16)*
Neutral	6 (24)	6 (24)	9 (36)	8 (32)
Positive	11 (44)	12 (48)	11 (44)	12 (48)
Subsequent course of action				
Full direct disclosure	1 (4)	0 (0)*	0 (0)*	2 (8)*
Use of euphemism	6 (24)	6 (24)	6 (24)	6 (24)
Partial disclosure	16 (64)	15 (60)	15 (60)	14 (56)
Indirect disclosure	1 (4)	2 (8)	1 (4)	1 (4)
No disclosure	1 (4)	1 (4)	1 (4)	1 (4)

* Data is missing for one or two respondents.

DISCUSSION

In this study, a majority of the oncologists (72%) surveyed were more likely to disclose a diagnosis of cancer to the patient first. This is in contrast to a previous local study, which found that a majority of physicians (90.4%) would usually tell the patient's family the diagnosis but less than half (43.6%) would tell the patients themselves.⁽¹⁷⁾ The change from a family-centred medical approach to a more patient-centred one in Singapore, as indicated in the current study, may reflect the increase in both medical ethics education among oncologists as well as patient awareness and autonomy, which is likely to accompany an increasingly westernised society.

Our study also found that family resistance was the only significant predictor of reluctance to disclose a diagnosis of cancer ($p = 0.01$). A similar finding has been reported in Asian studies, where families often oppose full disclosure in order to protect the patient from psychological distress.^(6,13,18,19) Surprisingly, there were no significant patient or disease factors that predicted the willingness of an oncologist to disclose a diagnosis of cancer. This is in contrast to a previous study in Japan, where factors such as 'non-curability' and 'inability of patient to understand the information', were significant predictors of non-disclosure.⁽⁶⁾ Many studies have shown that with adequate disclosure, the patient can make autonomous decisions on the plan of care and informed decisions on interventions and treatment regimens, which leads to an overall decrease in morbidity and better outcomes.⁽²⁰⁻²²⁾

Oncologists surveyed in this study indicated that they were uncomfortable with family requests for non-disclosure. This was mainly due to the fact that such a request "undermines patient autonomy" and "did not allow for informed consent", and therefore, oncologists were unlikely to accede to the request. Oncologists who were neutral to such requests felt that the request was "culturally acceptable". Many oncologists also felt that acceding to the family's request would have negative impact on patient-doctor and family-patient relationships. In order to circumvent this problem, many opted to use euphemisms or performed partial disclosures. This is in contrast to a 1997 local survey, which showed that 40% of terminally ill patients were unaware of their diagnoses,⁽²³⁾ and another local study which showed that 84% of physicians would accede to a family's request to not reveal the diagnosis to the patient.^(17,23) This shifting trend could indicate that in recent years, physicians in Singapore have been moving away from the family-centric and paternalistic models of decision-making, and are placing more emphasis on patient autonomy. The strategies that oncologists in this survey found most useful when dealing with family collusion included "finding out patient preferences", "explaining the benefits of disclosure to the family", "finding out the family's view point" and "explaining to the family a doctor's obligation to disclose the diagnosis".

There are several limitations to this study. Firstly, the sample size was small, and therefore, inadequate to detect any associations between demographic factors and the reluctance to

fully disclose a cancer diagnosis. The small size also precluded any comparison of the approaches to disclosure adopted by radiation, medical and surgical oncologists. Secondly, as the response rate was low (50%), there is the possibility of respondent bias in our data. Additional attempts to increase the response rate by extending the length of the study did not increase the number of participants. Future studies should consider both the oncologists' busy schedule, as well as the sensitivities associated with a questionnaire on disclosure practices so as to maximise response rates. Thirdly, with the recent increase in the emphasis on medical ethics and autonomy, physicians may be less inclined to reveal disclosure practices that may be considered 'unethical'. This may have led to false negative associations in our study. However, even with this sensitive information bias, we were able to detect a significant association between family resistance and reluctance to fully disclose a diagnosis of cancer. Lastly, since this study was conducted solely at one tertiary centre in Singapore, the results may not be representative of oncologists as a whole in the country. Larger studies are needed to confirm the results of this study.

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