# Disclosure Preferences Towards Terminally III Patients in Singapore: Are We Ready to Confront the "Elephant in the Room"?

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#### **ABSTRACT**

The disclosure preferences of dying patients, family members, palliative care professionals and members of the public in Singapore and the actual disclosure practices of palliative care professionals were investigated with 115 participants. Discrepancies between patient and family member preferences were evident. Family members tended to want to know the patients' diagnosis and prognosis more than the patients themselves wished for the family to be informed. Family members also wanted patients to be informed of their diagnosis

**Key Words:** cancer; disclosure; diagnosis; prognosis; Singapore.

and prognosis even though they believed that the patients sometimes preferred otherwise. In the situation where family members were asked about their own disclosure preferences should they have a terminal illness, more preferred full disclosure of prognosis to self than to their family. The finding that people imagining a terminal illness reported wanting to know their own (hypothetical) diagnosis and prognosis more frequently than actual patients do is a salient reminder about the danger of making assumptions about patient preferences. Concerns reported by palliative care professionals showed that they are careful about the potential impact their disclosure may have on patients. Palliative care professionals nonetheless did tend to respect family member wishes over those of the patients. They perceived their lack of communication skills in delivering bad news as the main barrier to open communication. The allied healthcare participants in this study appeared to be more confident in communicating bad news than the doctors and nurses, but their expertise did not seem to be fully utilised. Thus, there may be some potential for closer collaboration and cross training amongst the professions to increase self-efficacy in delivering bad news.

#### INTRODUCTION

Research into the delivery of diagnostic and/or prognostic information about terminal illnesses to patients includes surveys of disclosure preferences of patients and family members;<sup>1-8</sup> physician attitudes and practices in disclosure of diagnosis and prognosis; <sup>9-11</sup> the investigation and provision of strategies to help clinicians deliver bad news e.g.,<sup>12, 13-15</sup> and the exploration of cultural differences in information preferences of physicians, patients and their families.<sup>14, 16-23</sup>

Kirk et al. 18 found that almost all of their Australian and Canadian patient-family dyads wanted prognostic information and their relatives respected their wishes. Similar but larger scale quantitative studies have also been conducted on cancer patients and their caregivers in Asian cultures such as a study in China of 382 patients and 482 caregivers, one in Taiwan of 618 patient-family dyads<sup>2</sup> and one in Korea of 380 patients and 281 family members. 4, 24 An Indian study showed that most radiation oncologists believed that patients were keen on knowing their diagnosis and prognosis.<sup>25</sup> A consistent trend in many Asian studies was that patients wanted to be given information about their diagnosis and/or prognosis even though their family members preferred otherwise. This finding of discrepancies between the preferences of patients and family members has thus been observed both in Asian and non-Asian settings.<sup>26-30</sup>

Tang & Lee<sup>17</sup> suggested that the arguments around disclosure of diagnostic and prognostic information to terminally ill patients have largely evolved around four key ethical principles: patient autonomy, self-determinism, beneficence and non-maleficence. Patient autonomy and self-determinism are often associated with Western cultures that value individual rights including rights to information and freedom to make informed decisions about healthcare matters such as decisions about medical interventions, acceptance of or withdrawal from resuscitative efforts and choices on preferred place of care and death. Conversely, the principles of beneficence and non-maleficence are often presented as reasons for opposing full or direct disclosure. It is believed, especially in family and community oriented cultures, that families and sometimes physicians, have a duty to protect the dying from potential harm associated with knowing their diagnosis and prognosis (e.g., increased hopelessness and despair in the dying patients, or increased risk of suicide). In these cultures, family autonomy tends to overrule that of individuals and as a result, physicians often respect family wishes to conceal diagnostic and/or prognostic

information from patients. 14, 17

Open disclosure promotes patient autonomy and selfdetermination, fosters more trust in the physician-patient relationship, and helps patients to make better informed choices about their preferred treatment options. 10, 31 Terminally ill patients can also make plans and prioritise their remaining time to focus on important issues or complete unfinished business.<sup>32</sup> Studies have suggested that patients who were aware that their illness was terminal reported higher spiritual well-being<sup>33</sup> and had better mental health and quality of death outcomes.<sup>4, 34</sup> The need to obtain patient informed consent for most diagnostic and treatment protocols also necessitates that physicians openly discuss the patients' conditions with them. 13 The costs to hospice workers in terms of stress caused by keeping secrets from patients have been repeatedly noted. 35

While there are significant variations in patient and family disclosure preferences due to ethnic, cultural and personal differences, there is now wide consensus concerning a need to evaluate and respect individual preferences while bearing in mind potential cultural differences, instead of forming stereotypical opinions about their disclosure preferences based on ethnic or cultural backgrounds. <sup>14, 36-38</sup>

Research in both Western and Eastern countries consistently indicates that the level of disclosure of diagnosis and prognosis to patients by medical professionals (especially doctors) lags behind that preferred by the patients.<sup>1, 2</sup> Many reasons have been cited as possible barriers to disclosure including prognostic uncertainty;<sup>32</sup> fear by doctors and/or families of creating despair and hopelessness in the patients;<sup>12, 39, 40</sup> respect for patient family/caregiver instructions on non-disclosure <sup>10</sup>, and doctors' perceived lack of appropriate communication skills to deliver bad news in a respectful and sensitive manner.

# SINGAPOREAN STUDIES ON DISCLOSURE PREFERENCES

The study of family member perspectives has significance in Singapore which is a very cosmopolitan country but with strong collectivistic roots. In studies from other Asian cultures, <sup>1, 37</sup> some family members were found to have a tendency to override patient wishes to know their diagnosis and/or prognosis due to their fear of upsetting the patients. This phenomenon may pose ethical

dilemmas for palliative care professionals who may be trying to balance interpersonal responsibility towards the family with respect for the individual autonomy of the patient.41

An early Singaporean survey to investigate doctors' views about revealing a diagnosis of cancer to the patient 42 found that nearly all (90.4%) would reveal the diagnosis to the family, but less than half (43.6%) would inform the patient. The present study sought to determine whether there had been a change in practice towards more open disclosure along with the recent shift from a paternalistic to a patient-centred model of care.

The multidisciplinary team approach adopted in modern hospices has also led to greater involvement of other allied healthcare professionals (e.g., medical social workers, counsellors and psychologists) in the basic care of the patients and their families. Thus, the views of allied healthcare professionals were also solicited in this study.

The main aim of the current research was to investigate the disclosure preferences of dying patients, family members, palliative care professionals and members of the public in Singapore and to establish the actual disclosure practices of palliative care professionals.

#### **METHOD**

# **Participants**

The participants (115) consisted of 6 terminally ill patients, 30 family members of existing or deceased terminally ill patients, 42 public participants, and 37 palliative care professionals. The palliative care professionals group included 15 doctors, 16 nurses, and 6 allied healthcare professionals (medical social workers, counsellors, and occupational therapist).

#### Measures

A questionnaire (with slight differences for different samples groups) was constructed to elicit participant characteristics, views and preferences on diagnosis and prognosis disclosure. The first section covered demographics, disease characteristics, and past experience with death. Section two considered disclosure preferences. Items relating to disclosure were extracted mainly from the interview protocol used in the study by Yun et al.<sup>4</sup>

Questions included asking participants whether they would like to know their diagnosis and prognosis, whether they would prefer their family to be told, the preferred informant (who to tell), disclosure pathways (how conveyed), timing (when), settings (where) and extent of disclosure. A copy of the questionnaire is available from the authors.

# Procedure

To be eligible for this study, participants had to be above 21 years old, cognitively competent and able to communicate in English, Mandarin or Cantonese. Patients and most of the family members and palliative care professional participants were recruited through two hospices in Singapore. Potential patient and family member participants were approached by palliative care professionals (doctors, medical social workers and nurses). Interested participants gave consent for a researcher to contact them for the interview/survey. Emails to recruit other family members, palliative care professionals and public participants were sent out. Target numbers were 30 each for the patients and family members group and 40 for the palliative care professionals and public participants group. Due to difficulties in recruiting terminally ill patients within the time frame of this study, only six patients were successfully recruited. Institutional and patient consents were obtained before the study proceeded.

#### RESULTS

The demographic characteristics of the participant groups are provided in Table 1. The majority of the participants were Chinese. Disclosure preferences for diagnostic and prognostic information relating to terminal illness from patients, family members and public participants are provided in Table 2.

All patients claimed that they knew their diagnoses and all patients reported that their family members were aware of their diagnosis. Half of the patients (3/6) reported that they were aware of their prognosis and most patients (4/6) indicated that their family knew their prognosis. Most patients wanted to know their diagnosis and prognosis (4/6) and also wanted their family to be informed.

All family members reported being aware of patient diagnoses. Family members' estimations of the percentages of patients who wanted to know their diagnosis and prognosis were close to the actual rate reported by the patient group (around two thirds). However, a sizable majority of family members would want the patients to be informed of their diagnoses and prognoses even though they predicted that patients themselves would want to be informed at a much lower rate for both diagnosis and prognosis.

Nearly all of the family members indicated that they wanted to know the patients' prognosis (27/30), even though they predicted that proportionately fewer of the patients would want their family to know their prognosis and even though they were less likely to want family members to be informed of their prognosis should they themselves have a terminal illness.

In the hypothetical situation where respondents were faced with their own terminal illness, all family members reported wanting to know their diagnosis but only around three quarters would want their family to know their diagnosis. The majority would want to know their own prognosis and would also want their family to know this. Nearly all of the public participants would want to know their diagnosis while fewer wanted their family to be informed of this. Nearly all would want to know their own prognosis and would want their family to know this too. Fisher's exact tests showed that patients who actually had a terminal disease were less likely than family members and the public who imagined having a terminal disease to want to know their diagnosis (p = .014) and their prognosis (p = .006).

Table 1. Demographic Characteristics (Frequencies and Percentages) by Groups (N=115)

	Patients $(n = 6)$	Family $(n = 30)$	Public $(n = 42)$	Professionals $(n = 37)$	
Age (in years)					
Mean (SD)	64 (8.2)	43 (11.9)	36 (11.4)	37 (8.6)	
Range	55 - 78	27 - 79	22 - 61	23 - 55	
	Number and Percentage of Participants				
Sex					
Female	1 (16.7)	21 (70.0)	30 (71.4)	29 (78.4)	
Male	5 (83.3)	9 (30.0)	12 (28.6)	8 (21.6)	
Ethnicity					
Chinese	6 (100.0)	28 (93.3)	39 (92.9)	34 (91.9)	
Malay		1 (3.3)		2 (5.4)	
Indian			2 (4.8)		
Eurasian		1 (3.3)			
Others			1 (2.4)	1 (2.7)	
Marital status					
Single	1 (16.7)	13 (43.3)	23 (54.8)	16 (43.2)	
Married	4 (66.7)	12 (40.0)	17 (40.5)	18 (48.6)	
Widowed	1 (16.7)	4 (13.3)	1 (2.4)	2 (5.4)	
Divorced/separated		1 (3.3)	1 (2.4)	1 (2.7)	
Religion					
Yes	6 (100.0)	20 (66.7)	32 (76.2)	32 (86.5)	

Table 2. Disclosure Preferences on Diagnosis (Dx) and Prognosis (Px)

	Number and Perce	Number and Percentage of participants who agree		
	Patients	Family	Public	
	(n = 6)	(n = 30)	(n = 42)	
Diagnostic information				
Aware of patient's Dx	6 (100)	30 (100)	n.a.	
Thinks patient is aware of Dx	n.a.	25 (83.3)	n.a.	
Would like patient to know Dx	n.a.	27 (90.0)	n.a.	
Thinks patient wants to know Dx	n.a.	20 (66.7)	n.a.	
Wants to know own Dx *	4 (66.7)	30 (100)	41 (97.6)	
Wants family informed of own Dx $^{*}$	5 (83.3)	23 (76.7)	33 (78.6)	
Family aware of own Dx	6 (100)	n.a.	n.a.	
Prognostic information				
Aware of patient's Px	3 (50.0)	28 (93.3)	n.a.	
Patient knows that family has information				
about his/her Px	n.a.	18 (60.0)	n.a.	
Would like patient to know Px	n.a.	23 (76.7)	n.a.	
Thinks patient wants to know Px	n.a.	19 (63.3)	n.a.	
Wants to know patient's Px	n.a.	27 (90.0)	n.a.	
Wants to know own Px *	4 (66.7)	24 (80.0)	41 (97.6)	
Wants family informed of own Px $^{\ast}$	5 (83.3)	24 (80.0)	38 (90.5)	
Family aware of own Px	5 (83.3)	n.a.	n.a.	

<sup>\*</sup> For the family members and public group these questions referred to a hypothetical situation of an imagined terminal illness.

When asked about the possible effects of disclosure of diagnosis, more than half of the palliative care professionals thought that disclosure had a positive effect on patients while almost half responded that it "depends" on various factors, such as: patient perceptions about their conditions; their level of acceptance or readiness to receive news; their age, culture and past experiences with death; and family member personalities and family dynamics. Some of the positive effects mentioned were that disclosure enables the patients to take control by making informed treatment decisions, and provides them with an opportunity to "complete their wishes". Negative effects included the fear that the patients may not be able to accept the news.

Nearly all of the doctors (93%) reported that they tend to disclose diagnostic and/or prognostic information to patients who have a terminal illness. The main reasons cited by palliative care professionals for wanting to disclose diagnoses were: the need to respect the patients' wishes (90.9%); that they themselves would like to know their diagnosis if they had a terminal illness (93.8%); and that diagnosis disclosure facilitates future treatment and investigation work (90.6%).

There was some evidence that health professionals felt inadequately prepared to handle disclosure situations. Doctor reports included anxiety over how the patients might respond, being inadequately prepared to handle such interactions and knowledge that patients' family had requested that patients should not be told. Nurses reported a broad range of reasons for not disclosing, particularly experiencing discomfort with those hearing bad news.

# **DISCUSSION**

In order to determine patterns of consistency or difference, the present study concurrently explored disclosure preferences from the perspectives of the patient, family members of terminally ill patients, the public and palliative care professionals in Singapore.

A majority of the patients, family members and public participants in this study preferred an open disclosure of diagnosis and prognosis, both for the patients and to family members. The main reason cited for supporting disclosure was a right to know.

While all patients claimed that they were aware of their diagnosis not all knew their prognosis. For those not aware of their prognosis the Japanese concept of amae - meaning "dependency" - where patients rely on the doctors to take care of or make decisions for them<sup>41</sup> seemed to be applicable. In contrast, the majority of the patient preferences were consistent with the concept of individual autonomy. It is important to note that both approaches were acceptable from the patients' perspectives.

Whether non-disclosure creates ambiguity that may have a negative impact on patient well-being<sup>32</sup> or is an adaptive way of coping with illness is unclear as the current patient sample size was too small for any generalisations to be made. Cherny<sup>43</sup> has provided an overview of patient communication controversies and drawn attention to the need for a nuanced approach including an appreciation of the importance of misconceptions relating to culture. Similarly, the current findings hope to serve as an anecdotal account to emphasise individual variations in disclosure needs.

# FAMILY MEMBERS

Discrepancies between patient and family member preferences were evident. Family members tended to want to know the patients' diagnosis and prognosis more than the patients themselves wished for the family to be informed. Family members also wanted patients to be informed of their diagnosis and prognosis even though they believed that the patients sometimes preferred otherwise.

In the situation where family members were asked about their own disclosure preferences should they have a terminal illness, their stance reversed. In this context, more preferred full disclosure of prognosis to self than to their family. These findings suggested a double standard and a paternalistic approach<sup>41</sup> when considering disclosure to patients. Such double standards may be rooted in the positively regarded "self-sacrificial" value that a traditional collectivistic society prizes.

A paternalistic view towards disclosing information to the patients/family members is consistent with research from Taiwan where participants indicated that patients' relatives tended to subscribe to the principle of beneficence (by "protecting" the family from the truth of their diagnosis) whereas the patients themselves preferred to adopt the principle of autonomy (wanted to know their own diagnosis) for themselves.<sup>44</sup> Similarly Kakai <sup>41</sup> found that Japanese participants appeared to favour a direct communication style for their own diagnosis but viewed an indirect, non-disclosure or ambiguous (partial) disclosure to the patient as a more "ethical style" of communicating. According to Kakai, this stemmed from the Japanese's cultural emphasis on harmony and their fears of crushing hope or burdening others.

The finding that people imagining a terminal illness reported wanting to know their own (hypothetical) diagnosis and prognosis more frequently than actual patients do is a salient reminder about the danger of making assumptions about patient preferences.

# THE HARBINGERS' DILEMMA

Doctors and nurses were more likely to reveal diagnosis than prognosis directly to the patients. Furthermore, fewer doctors would provide prognosis directly to the patients than to their family members. These findings were consistent with past research where healthcare professionals expressed reservations about disclosing prognosis information to the patients.<sup>39</sup> Compared to a much earlier Singaporean study by Tan et al., 42 there was an increase in willingness amongst doctors to reveal diagnosis to patients (from 43.6% in the 1993 study to 93% in this study). Despite palliative care professionals' beliefs in respecting individual patient rights and wishes, the tendency remained for them to respect family members' wishes over those of the patients.

Nearly half of the palliative care professionals reported that the effects of disclosure may depend on certain patient-related factors such as personality, level of acceptance and readiness, and needs for control and to plan for the future. Some palliative care professionals also felt the need to understand the patients more before revealing information to them. Such concerns showed that palliative care professionals are careful about the potential impact their disclosure may have on the patients.

Some doctors and nurses felt inadequately prepared to reveal information and some expressed concerns about family requests for non-disclosure. Some doctors and allied healthcare participants were also apprehensive about handling conflicting instruction between families and patients. Collectively, these factors may explain why palliative care professionals chose to reveal information to family members first before deciding whether to inform the patients.

#### CLINICAL IMPLICATIONS

In this, the first Singaporean study to look at the disclosure preferences of patients, family members, the public and palliative care professionals concurrently, a majority but not all of the participants reported that they would like to be informed of their diagnosis and prognosis if they had a life-threatening illness. Family members adopted a paternalistic approach with respect to disclosure of diagnosis and prognosis in that they wanted more disclosure for the actual patients than they would prefer if they themselves were patients. The public group also revealed similar reservations about burdening family members with information regarding their (potential) illness. This presents a challenge for clinicians who face ambiguous preferences from their patients and their families.

Clinical practices in palliative care have clearly changed. In the current study, nearly all of the doctors (93%) tended to reveal a diagnosis to patients, which is a major change from the 43.6% reported by an earlier Singaporean study (Tan et al., 1993). Nevertheless the current study revealed that a majority of palliative care professionals still have a tendency to consider family member wishes above those of the patient.

Discrepancies between the preferences of people imagining a terminal illness versus those of real patients serve to remind clinicians of the danger of making assumptions about patient preferences.

While clinic guidelines about communicating prognosis and end of life issues exist, 45 a major barrier shared by doctors and nurses (but not the allied healthcare participants) was their perceived lack of communication skills in breaking bad news. All palliative care professionals agreed that having more training on communication and management skills in dealing with end-of-life issues was needed. While Kumar et al. 46 have described revised training intended to improve general physician-patient communication in palliative care, interestingly, the allied healthcare participants in this study appeared to be more confident in communicating bad news than the doctors and nurses, but their expertise did not seem to be fully utilised. Thus, there may be some potential for closer collaboration and cross training amongst the professions to increase self-efficacy in delivering bad news.

## **LIMITATIONS**

The attempt to understand disclosure issues from the perspectives of professionals, patients, family members and the general public was severely restricted due to having such a small sample in each group hence the results cannot be regarded as definitive. Similarly the numbers of non-Chinese respondents in the study were too small to allow any conclusions about non-Chinese Singaporeans or for any cultural sub group comparisons to be made. These limitations mean that only simple descriptive statistics could be presented. Finally, slightly different questions were (of necessity) used for each group. Collectively these limitations mean that the study should be seen as qualitative in nature.

The difficulty experienced in recruiting terminally ill patients may be indicative of the challenges that remain in developing open communications between palliative care professionals, patients and families and of shortcomings in terms of attending to the psychological needs of the dying.

#### ACKNOWLEDGEMENTS

Special thanks to the patients for their generosity in sharing their precious time and to the family members who so willingly offered their opinions despite the occasional difficult moments some experienced as memories of their deceased loved one surfaced. Sincere thanks to Dr Tan Yew Seng from Assisi Hospice and Mr Edward Poon from the Dover Park Hospice for their ardent support in this study and to various staff of Assisi Hospice (Ms Peh Cheng Wan, Mr Fong Yee Leong, Ms Jayne Leong, Ms Lim Mooi Hong, and Ms Lai Mee Horng)

and Dover Park Hospice (Dr Mervyn Koh) for their kind assistance in the difficult recruitment task.

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