

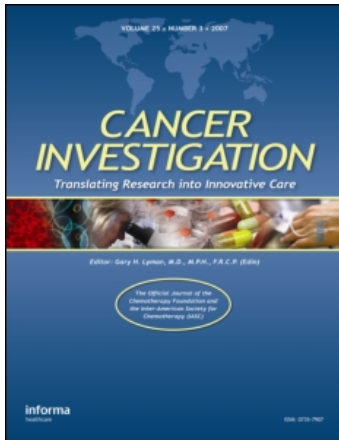
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Congruence of Knowledge, Experiences, and Preferences for Disclosure of Diagnosis and Prognosis between Terminally-Ill Cancer Patients and Their Family Caregivers in Taiwan

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ORIGINAL ARTICLE

Congruence of Knowledge, Experiences, and Preferences for Disclosure of Diagnosis and Prognosis between Terminally-Ill Cancer Patients and Their Family Caregivers in Taiwan

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ABSTRACT

Background. Over the last 40 years, studies have shown cultural differences in attitudes toward truth telling at the end-of-life. Nevertheless, the argument that cancer patients from an Asian culture have different preferences about information disclosure that necessitate significantly modifying information disclosure practices has not been validated by direct investigation from patients' points of view. **Methods.** Six hundred seventeen dyads of patient-designated family caregivers across 21 hospitals throughout Taiwan were surveyed and interviewed by a semistructured interview guide. Percentage of agreement, kappa coefficients, McNemar tests, and paired t-tests were conducted to examine the extent of congruence of knowledge, experiences, and preferences for disclosure of diagnosis and prognosis between the dyads. **Results.** There were substantial discrepancies in the knowledge and experiences of being informed about the diagnosis and prognosis between Taiwanese terminally-ill cancer patients and their family caregivers (kappa values ranged from 0.08 to 0.44). Cancer patients strongly proclaimed their superior rights to be informed about their disease over their family and preferred their physicians to inform themselves before releasing any information to their family caregivers. **Conclusion.** The arguments that cancer patients from an Asian culture (i.e., Chinese/Taiwanese culture) have different preferences regarding being informed of their diagnosis and prognosis and that family members have legitimate superior power in decision making could not be supported by data from this group of terminally-ill cancer patients. Physicians need to respect patients' preferences rather than routinely taking the family's opinions into consideration first in the event of disagreement. Equipped with adequate information, terminally-ill cancer patients from Asia may have better opportunities to make end-of-life care decisions that are in accord with their wishes.

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Keywords: Information disclosure, Truth telling, End-of-life care, Congruence of preferences for information disclosure.

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Over the last 40 years, studies have shown cultural differences in attitudes toward truth telling, life-prolonging, and decision making styles at the end-of-life. In the United States, Oken's (1) and Novack's (2) studies mark the transition from beneficence and paternalism to respect for patient autonomy as the reigning principle in contemporary medical ethics—a movement away from rigid paternalism toward an approach more responsive to patients' wishes. Cancer patients' information needs are substantial. Surveys (3–5) have shown that patients were unanimous in their view that they want accurate, even if grim, information about their diagnosis and prognosis. However, doctors worldwide seriously underestimate the information needs of their cancer patients (6–8) and, consequently, leave patients inadequately informed and prepared to participate in the decision of selecting the most desirable treatment (9, 10). A key dilemma in communicating disease-related information to cancer patients is how to respond to the family's requests to withhold information from patients. Mystakidou and colleagues (11) concluded from their review of published studies that family requests to withhold information from the patient occurred within every ethnic group, including those from Southern and Eastern Europe (i.e., Spain and Greek), Africa, France, Iran, Panama, Japan, Singapore, China, and Saudi Arabia.

In Asian countries, such as Japan and China/Taiwan, a “family-consent for disclosure” (12) approach commonly is adopted based on the assertions of filial piety and the relative power attributed to the social world. Families are expected to protect their parents or those they are caring for from dangers or threats. Therefore, in order to protect patients from the harm associated with knowing their diagnosis and prognosis, there is a need to keep information about the disease and prognosis from the patient and to release disease-related information only to patients' families (12–14). Furthermore, in Asian cultures a model of family autonomy is well-recognized in which family members have legitimate superior decision making authority even over fully competent patients (15, 16). Physicians' respect for patient autonomy frequently is subordinate to the power of family (13–15). Consequently, in the case that families decide that, based on their judgments of the best interest of the patients, diagnosis and prognosis information should not be disclosed to the patients, physicians will withhold the information from the patients in accord with the families' requests.

In explaining the phenomena for withholding diagnosis and prognosis information from cancer patients, it has been suggested that it may be difficult to disentangle the cultural practice of beneficence toward the patient from family's or physicians' reluctance to disclose negative information because of their own anxieties (17, 18). Furthermore, the argument that cancer patients from an Asian culture have different preferences about being informed of their diagnosis and prognosis that dictate significantly modifying information disclosure practices has not been validated by evidence-based studies. Preferences for information disclosure in Asian countries were explored primarily from surveys of general public or noncancer patients (5, 13, 19). Results from those studies may be different from the opinions of patients who were directly impacted by cancer and who need to

make day-to-day treatment decisions. Except for a few studies (20, 21), responses expressed directly from cancer patients were predominantly based on anecdotal case reports (22, 23). Little is known of the worldviews of cancer patients from Asian cultures. In addition, comparisons of preferences for information disclosure between cancer patients and their family caregivers have not been extensively investigated, including in Western countries. It is unclear whether the differences in disclosing disease-related information to cancer patients between Western countries and Asia are simply because they are at a different stage of evolution of ethical practices or they truly reflect major differences in cultural values. The attitudes regarding information disclosure to cancer patients in Asian cultures such as in Chinese and Taiwanese cultures should be better characterized and explored, especially from both patients' and family's opinions. Therefore, the purposes of this study were to: (1) compare Taiwanese terminally-ill cancer patients' and their primary family caregivers' knowledge of their diagnosis and prognosis; (2) identify diagnosis and prognosis disclosure practices of physicians as experienced by terminally-ill cancer patients and their primary family caregivers; and (3) explore attitudes toward the well-recognized practice of disclosing information to family, even respecting family's opinions not to disclose the life-threatening diagnosis and prognosis to patients, from cancer patients' and their family caregivers' points of view. Based on the facts that Chinese Americans are one of the fastest growing ethnic groups in the United States and worldwide, Chinese/Taiwanese represent nearly a quarter of the world's population, findings from this study also can provide insight to clinical care around the world.

METHODS

Sample

From February 2003 to May 2004, a survey was conducted across 21 hospitals throughout the country. These hospitals provide the great majority of care for cancer patients in Taiwan. The human subject research review committees of the study hospitals granted approval for this study and permission for the researchers to contact patients was obtained from the primary physicians of the study subjects. Due to the infeasibility to obtain a complete list of terminally-ill cancer patients from the study sites and the difficulties in recruiting patients at end-of-life care research (24), subjects were recruited by a convenience sampling strategy. Eligibility criteria for subjects were patients: (1) who had a disease at a terminal stage, which was continuing to progress with distant metastases and was unresponsive to current curative cancer treatments; (2) who were cognitively competent; (3) who could communicate with the data collectors; and (4) whose designated family caregivers also agreed to participate in the survey. The family caregiver was defined as the person most involved in the patient's care and health care decision making.

Potential subjects were identified and referred by primary physicians of the patients in each study site by the request of

the research review committees. Primary physicians were given a detailed explanation regarding the purpose of the study. The patients' names were asked to give to the data collectors without judging the emotional readiness of the patients to talk about their preferences for information disclosure. After verifying the eligibility of patients, data collectors invited potential patients to participate in this study without asking permission of the contacted patient's family to avoid the exclusion of patient due to any conflict of opinion between the family caregiver and the patient's participation. Written informed consent was obtained from all participants, separately from patients and their family caregivers.

Data collection process

Data were gathered from the patients' medical records and from in-person interviews with patients as well as their designated family caregivers. Study subjects were asked a series of questions regarding knowledge, experiences and preferences for information disclosure. Interview guides were developed based on an extensive review of existing literature and have been used and validated in a previous study (25). In brief, *diagnosis and prognosis* were defined as whether the disease was a cancer and curability of the disease, respectively, which were in line with the common definitions of diagnosis and prognosis from published studies (3, 4). *Detailed disease-related information* included: location of cancer, the nature of malignancy, the extent of metastasis, chance of survival, and expected length of survival. The degree of expectation for physicians to disclose information of diagnosis and prognosis to (a) patient personally, (b) the family, (c) patient first followed by informing the family, and (d) the family first followed by informing the patient was measured on a 5-points Likert scale (1 = strongly not expected; 5 = strongly expected).

Subjects were first asked whether they knew their diagnosis and prognosis separately. Subjects who reported knowing their diagnosis and/or prognosis were asked to indicate the name of their disease and whether it was curable or incurable. Experiences of being informed of diagnosis, prognosis, and detailed disease-related information were only explored for patients reporting that they knew their diagnosis and prognosis. Participants were invited to share their knowledge, experiences, and preferences for physician disclosure of information in detail. Consenting patients and their designated family caregivers were interviewed separately to ensure the independence of the responses from each party.

To standardize presentation of questions, interviewers were trained in conducting the interviews through small-group didactic sessions and individually coached by the principal investigator and two senior project managers. At the end of the training, consensus about data collection was reached and each data collector had demonstrated sufficient data collection skills such that the principal investigator was satisfied with their competence. The initial interviews of each data collector were conducted under the supervision of the principal investigator or one of the two senior project managers.

Responses to the research questions were coded based on the trained data collectors' judgments of the implications of the interviews. At the training stage of this study, participant responses were interpreted and coded by both the trained data collector and the supervisor separately. Any discrepancies in the coded responses were discussed and resolved. Satisfactory consensus about coding of responses was achieved before each data collector was allowed to conduct interviews independently. The principal investigator served as a resource person for resolving problems or any concerns with the data collection process.

Statistical analysis

Descriptive statistics were computed to describe the characteristics of subjects and to present frequencies of information disclosure and the extent of preferences for information. The extent of differences in knowledge and experiences of being informed of diagnosis and prognosis between terminally-ill cancer patients and their designated family caregivers was analyzed using the McNemar tests to examine differences in the proportions of binominal responses for paired data. In addition to percentage of agreement, kappa coefficients were computed to assess the congruence between terminally-ill cancer patients' and their family caregivers' knowledge and experiences of physician disclosure of information to correct or adjust for the amount of agreement that can be expected to occur by chance alone (26). Criteria proposed by Landis and Koch (27) for kappa as a measure of the strength of agreement were followed: ≤ 0.20 , poor; 0.21–0.40, fair; 0.41–0.60, moderate; 0.61–0.80, substantial; 0.81–1.00, almost perfect. Paired *t*-tests were conducted to explore the degree of preferences for physicians to disclose information to (1) patient personally, (2) the family, (3) patient first followed by informing the family, and (4) the family first followed by informing the patient between the dyads of patients' and their family caregivers' points of view. All statistical analyses were conducted using Statistical Analysis System (SAS) version 8.2.

RESULTS

Characteristics of study samples

A total of 617 dyads of terminally-ill cancer patients and their family caregivers were recruited from 907 eligible patients (68.0 percent participation rate). Age was the only difference in sociodemographic and medical characteristics between the patient participants and nonparticipants. Patients participated in this study were significantly younger by 3 years than the nonparticipants by mean age ($p = 0.0003$). Except for gender, there were no differences in age and relationships with patients between the family participants and non-participants. More male family caregivers participated in this study ($p = 0.006$). The primary reasons given for declining to participate were a fragile physical condition (201 out of 273 patients who rejected to participate; 73.6 percent) for the patients and a lack of interest (161 out of 233 family caregivers who declined to participate; 69.1 percent) for the family caregivers.

Slightly over one-half of the patients (58.5 percent) were male. The median age of patients was 62 years old (range: 22–89 years). The majority of patients were married (83.9 percent), lived with their spouse (77.8 percent) and children (75.0 percent), and had an educational level equal to or less than high school (67.8 percent). The most common diagnoses of patient participants were lung cancer (30.0 percent), colon-rectal cancer (9.6 percent), hematological malignancies (9.4 percent), hepatoma (7.8 percent), and head and neck cancer (7.4 percent). The median length of time since diagnosis was 9 months (range: 1–288 months). At the time of interview, the diseases of one-fourth of patients had metastasized to bone, lung, liver, or brain.

Approximately two-thirds (63.4 percent) of the primary family caregivers were female and half of them (51.9 percent) were the patient's spouse, with the other 31.8 percent being one of the patient's children. The median age of family caregivers was 48 years old (range: 17–85 years). Over four-fifths (82.8 percent) of the family caregivers were married and 78.4 percent of them lived with the patient. The majority (87.2 percent) of the family caregivers had contacts with the patients daily.

Congruence of knowledge and experiences of being informed of diagnosis and prognosis

Approximately 90 percent of terminally-ill cancer patients reported that they knew their disease as cancer (Table 1) and 86.3 percent of them indicated that such knowledge came from the physicians' disclosure. Almost all of the designated family caregivers (99.5 percent) knew about the patient's cancer diagnosis and 96.5 percent of them reported having being informed by physicians. Overall congruence of knowledge and experiences of being informed of the patient's cancer diagnosis between terminally-ill cancer patients and their designated family caregivers was 90.0 and 86.5 percent, respectively. However, kappa values for the extent of congruence were 0.08 (95% CI: 0.01–0.16) and 0.17 (95% CI: 0.06–0.27) for knowledge and experiences of being informed of cancer diagnosis, respectively, indicating poor agreement between the two respondents on these issues. In addition, results from the McNemar tests showed that there were significant differences between terminally-ill cancer patients' and their designated

family caregivers' knowledge and experiences of physician disclosure of information about diagnosis.

Less than one-half and one-third of the patients indicated that they knew or had been informed of their prognosis (Table 1), respectively. The proportions of family knowledge and experiences of physician disclosure of prognosis were 66.7 and 57.5 percent, respectively. There were significant differences between the patients' and their family caregivers' knowledge and experiences of being informed of prognosis. Overall percentages of agreements were 67.9 and 63.7 percent, respectively. Kappa statistics for the extent of congruence were 0.38 (95% CI: 0.31–0.44) and 0.31 (95% CI: 0.25–0.38), respectively. Such kappa values imply that knowledge and experiences of being informed of prognosis between the two respondents were only fairly correlated.

Congruence of experiences of being informed of detailed diagnostic and prognostic information

In comparison with the experiences of being informed of diagnosis and prognosis, detailed disease-related information was reported as being disclosed less frequently to the patients and their family caregivers. Approximately one-half and one-quarter of the patients had been informed of the location of cancer and nature of malignancy or extent of metastasis, respectively (Table 2). For detailed prognostic information (expected length of survival and chances of survival), almost all of the terminally-ill cancer patients had never been informed. The proportions of family caregivers who had been informed of detailed diagnostic information ranged from 38.3 to 55.6 percent and less than 12 percent of family caregivers had ever been told of detailed prognostic information. The same patterns of significant differences between the patients' and their designated family caregivers' experiences of being informed of diagnosis and prognosis by their physicians were observed in the detailed disease-related information too. Kappa values indicated fair to moderate congruence in the experiences of being informed of detailed diagnostic information (ranged from 0.32 (95% CI: 0.24–0.39) to 0.44 (95% CI: 0.37–0.51)) and poor to fair agreement in detailed prognostic information between the two parties

Table 1. Comparison of knowledge and experiences of being informed of diagnosis and prognosis between terminally ill cancer patients and their families

Knowledge/Experience	N	Patients (%)	Family (%)	%*	Kappa** (95% CI)	McNemar*** (df = 1)
Diagnosis						
Knowledge	608	89.1	99.5	90.0	0.08 (–0.01, 0.16)	63.0
Experience	607	86.3	96.5	86.5	0.17 (0.06, 0.27)	46.9
Prognosis						
Knowledge	604	45.9	66.7	67.9	0.38 (0.31, 0.44)	81.8
Experience	600	30.5	57.5	63.7	0.31 (0.25, 0.38)	120.4

*Percentage of agreement.

** All kappa values are significant at $P < .0001$ level.

*** $P < .0001$.

Table 2. Comparison of experiences of being informed of detailed disease-related information between terminally ill cancer patients and their families

Variables	Patient (%)	Family (%)	%*	Kappa** (95% CI)	McNemar (df = 1) P
Diagnosis (N = 606)					
Location	48.8	55.6	72.5	0.44 (0.37, 0.51)	9.8 (P = .002)
Nature of malignancy	24.9	38.3	73.2	0.38 (0.30, 0.45)	39.9 (P < .0001)
Extent of metastasis	26.9	42.6	68.8	0.32 (0.24, 0.39)	46.8 (P < .0001)
Prognosis (N = 600)					
Expected length of survival	4.2	11.2	87.7	0.14 (0.03, 0.25)	23.8 (P < .0001)
Chance of survival	2.8	7.5	93.3	0.33 (0.17, 0.48)	19.6 (P < .0001)

*Percentage of agreement.
**All kappa values are significant at P < .0001 level.

(ranged from 0.14 (95% CI: 0.03–0.25) to 0.33 (95% CI: 0.17–0.48)).

Comparison of the extent of preferences for information disclosure to oneself versus to the counterpart

Regardless of the nature of information on diagnosis or prognosis, terminally-ill cancer patients in this study expressed a significantly stronger preference of their physicians to inform them personally (mean scores ranged from 3.11 to 3.20 on a 5-point Likert scale) (Table 3) than to inform their family members (mean scores ranged from 2.99 to 3.05). The patients also preferred their physicians to inform themselves before releasing any information to their family caregivers (mean scores ranged from 3.58 to 3.61). Correspondingly, the patient less preferred their physicians to inform their family caregivers prior to informing them (mean scores = 3.41 for both diagnosis and prognosis). However, a totally opposite direction of preferences was expressed by the family caregivers towards the expectations of physicians to disclose information to them personally versus to their ill family members.

Table 3. Comparison of expectations of information disclosure to oneself or to the counterpart

Variables	Patients Mean (SD)	Families Mean (SD)	t value*
Diagnosis (N = 595)			
Inform patients	3.20 (1.50)	2.51 (1.51)	11.45
Inform family	3.05 (1.49)	3.65 (1.56)	-10.60
Inform patients prior to informing family	3.61 (1.01)	2.75 (1.26)	14.68
Inform family prior to informing patients	3.41 (1.00)	3.79 (1.25)	-6.51
Prognosis (N = 587)			
Inform patients	3.11 (1.48)	2.28 (1.44)	13.01
Inform family	2.99 (1.47)	3.64 (1.55)	-11.09
Inform patients prior to informing family	3.58 (1.03)	2.65 (1.30)	15.48
Inform family prior to informing patients	3.41 (1.00)	3.73 (1.29)	-5.18

* P < .0001 by paired t-tests.

DISCUSSION

The strengths of this study include the large sample size and the first direct comparison of knowledge, experiences, and preferences of physician disclosure of information of diagnosis and prognosis between terminally-ill cancer patients and their family caregivers outside the Western countries. The first noteworthy finding from this study was that, taking the patient and the family subjects as a whole, there were significant differences in their knowledge and experiences of being informed of diagnostic and prognostic information. Diagnostic information was more likely to be known or be disclosed to terminally-ill cancer patients and their family caregivers than information on curability of the disease, expected length, and chances of survival. This phenomenon was also observed by Caruso and colleagues from Italy (28). In addition, general information on diagnosis and prognosis was more likely to be known and be released to the subjects than detailed disease-related information. Similar observations have been made by several groups of researchers (7, 29).

The development of specialized cancer units and centers in recent years in Taiwan and the rapid propagation of cancer-related information through the media and internet make it harder to conceal diagnosis information from patients and their families. However, the lack of adequate information on prognosis, such as curability of the disease and expected length or chances of survival, has significant implications for end-of-life care decision making for terminally-ill cancer patients and their family caregivers. In spite of the difficulties inherent in making an accurate prognosis (30) and the reluctance of physicians to communicate survival estimate to patients (10), empirical evidence (9) showed that terminally-ill cancer patients and their family tend to be over-optimistic with their prognosis. Consequently, based on their overestimated prognosis, aggressive and maybe futile treatments may be chosen and efficacies of such treatments may be overexpected (10). Adequate disclosure of prognosis information can assist in sensitive planning of appropriate treatments to balance the goals of supporting patient values and limiting the use of "futile" interventions at the end-of-life.

The second major finding from this study was that there were substantial discrepancies in the knowledge and experiences of

being informed about the diagnostic and prognostic information between terminally-ill cancer patients and their designated family caregivers. Kappa values also illustrated poor-to-fair congruence in the majority of issues examined in this study between the two respondents. Only the agreement of disclosure of location of cancer exceeds the threshold for a moderate association. Without exception, the family caregivers were more aware of and more likely to have had diagnostic or prognostic information disclosed to them than patients were. This phenomenon not only occurs in Taiwan but also was reported from England (31), the United States (7), Spain (32), Italy (33), and Greece (34).

At a time when terminally-ill cancer patients need honesty and support while trying to make important final life choices, a conspiracy of silence may envelop them and hinder adjustments. In contrast, Prigerson (35) documented that, whereas patient information preferences and sociodemographic characteristics do not significantly influence the patient's likelihood of death acknowledgment, the odd is increased if the terminal prognosis is disclosed to them and disclosed "matter-of-factly." Furthermore, without frank disclosure, patients may be left with wildly inaccurate impressions of their future and unable to prepare appropriately for the end-of-life care issues (10). Conversely, Bradley and colleagues (7) found that having discussions with terminally-ill patients about prognosis documented was significantly associated with having discussions of life-sustaining treatments and with having DNR orders. Scholars (36, 37) suggested that to maintain dignity, terminally-ill cancer patients must have a sense of control over their dying circumstances and must be able to make their own decisions and to preside over their own dying. Open disclosure of diagnosis and prognosis is a safety valve to promote control of decision making at the end-of-life by an autonomous, fully informed patient. Every effort should be made to facilitate open dialogue among patients, their family, and health care professionals no matter which ethnicity the patient belongs to.

In response to the common belief that the family is more valued than the individual in Asian culture and disclosure of cancer diagnosis and prognosis information has to be adjusted in accordance with the family's wishes, the findings have indicated the contrary. Cancer patients in this study strongly proclaimed their superior rights to be informed about their disease over the family. Taiwanese terminally-ill cancer patients had a higher preference for physicians to inform them personally than to inform their family members. They also preferred to receive information before their family members did. These findings were similar to the preferences of patients in Benson and Britten's (38) study from England, Marwit and Datson's (39) work from the United States, and research from Yun's group (40) in Korea.

The arguments that cancer patients from Asian cultures (i.e., Chinese/Taiwanese culture) have different preferences regarding being informed of their diagnosis and prognosis and that family members have legitimate superior power in decision making could not be supported by data from this group of terminally-ill cancer patients. Cancer patients in this study do want to know

and be informed of their diagnosis and prognosis if given the opportunity. It is important for families of Chinese/Taiwanese terminally-ill cancer patients to "hear" and honor the preferences for information of their loved ones. By facilitating understanding and communication between terminally-ill cancer patients and their family, health care professionals may increase the possibility for an appropriate end-of-life care decision being made to meet the needs of terminally-ill cancer patients.

The convenience sampling scheme may compromise the representation of the targeted population. The generalizability of the findings from this study may not be applied to terminally-ill cancer patients receiving care other than at the 21 study sites and residing in other geographic areas. Relying on physicians' referrals of potential subjects may further restrict the generalizability of the findings to terminally-ill cancer patients who were judged by primary physicians as "appropriate" to share their opinions. Patients who declined to participate in this study may have different knowledge, experiences, and preferences of diagnosis and prognosis disclosure than those who were "willing" to share their experiences and preferences in medical discussion. The heterogeneity of study population by sampling patients at various stages of their disease trajectories (as manifested by the wide range of time since diagnosis) may introduce another potential bias in study subjects. Patients with long disease periods may be more experienced in oncology treatments; therefore, there may be a higher likelihood for them to be informed of or learned about their diagnosis and prognosis. This study also did not verify patients' reports of physicians' information disclosure practices from physicians' point of views.

Despite these limitations, this study underscores important implications for clinical care. In contrast to the long-standing and well-recognized proposition that cultural differences dictate significantly modifying Western approaches in communicating with Asian cancer patients, findings from this study suggest that Taiwanese terminally-ill cancer patients share the same information needs as Western patients. They expressed a strong preference for physicians to inform them of diagnostic and prognostic information prior to disclosing information to their family members. Physicians need to seek and respect cancer patients' preferences rather than routinely taking the family's opinions into consideration first in the event of disagreement. Although not all Asian terminally-ill cancer patients want the same amount of information about their diagnosis and prognosis, the call is to honor the information preferences for those who wish to know about their diseases and the fate of their future. Equipped with and empowered by adequate information, terminally-ill cancer patients from Asia may have better opportunities to make end-of-life care decisions that are in accord with their own wishes (6, 41). Future research should be focused on investigating factors that will facilitate or impede disease-related information disclosure and communication among Taiwanese terminally-ill cancer patients, their family caregivers, and health care providers. Knowledge gained from such studies will highlight the directions for future interventions to close the gap between what terminally-ill cancer patients prefer and what they really get in relation to disclosure of diagnosis and prognosis of their disease.

By providing culturally sensitive care that is tailored to the patient's informational needs, ultimately the quality of end-of-life care may be improved.

REFERENCES

1. Oken, D. What to tell cancer patients: a study of medical attitudes. *JAMA*. **1961**, *175*, 1120–1128.
2. Novack, D.H.; Plumer, R.; Smith, R.L.; et al. Changes in physicians' attitudes toward telling the cancer patient. *JAMA*. **1979**, *241*, 897–900.
3. Jenkins, V.; Fallowfield, L.; Saul, J. Information needs of patients with cancer: results from a large study in UK cancer centres. *Br. J. Cancer* **2001**, *84*, 48–51.
4. Hagerty, R.G.; Butow, P.N.; Ellis, P.A.; et al. Cancer patient preferences for communication of prognosis in the metastatic setting. *J. Clin. Oncol.* **2004**, *22*, 1721–1730.
5. Fielding, R.; Hung, J. Preferences for information and involvement in decisions during cancer care among a Hong Kong Chinese population. *Psycho. Oncol.* **1996**, *5*, 321–329.
6. Fallowfield, L.J.; Jenkins, V.A.; Beveridge, H.A. Truth may hurt but deceit hurts more: communication in palliative care. *Palliat. Med.* **2002**, *16*, 297–303.
7. Bradley, E.H.; Hallemeier, A.G.; Fried, T.R.; et al. Documentation of discussions about prognosis with terminally ill patients. *Am. J. Med.* **2001**, *111*, 218–223.
8. Bruera, E.; Neumann, C.M.; Mazzocato, C.; et al. Attitudes and beliefs of palliative care physicians regarding communication with terminally ill cancer patients. *Palliat. Med.* **2000**, *14*, 287–298.
9. Lamont, E.; Christakis, N.A. Prognosis disclosure to patients with cancer near the end of life. *Ann. Intern. Med.* **2001**, *134*, 1096–1105.
10. Weeks, J.C.; Cook, E.F.; O'Day, S.J.; et al. Relationship between cancer patients' predictions of prognosis and their treatment preferences. *JAMA* **1998**, *279*, 1709–1714.
11. Mystakidou, K.; Parpa, E.; Tsilika, E.; et al. Cancer information disclosure in different cultural contexts. *Support Care Cancer* **2004**, *12*, 147–154.
12. Akabayshi, A.; Fetters, M.D.; Elwyn, T. Family consent, communication, and advance directives for cancer disclosure: a Japanese case and discussion. *J. Med. Ethics.* **1999**, *25*, 296–301.
13. Blackhall, L.J.; Frank, G.; Murphy, S.; et al. Bioethics in a different tongue: the case of truth-telling. *J. Urban Health.* **2001**, *78*, 59–71.
14. Elwyn, T.S.; Fetters, M.D.; Gorenflo, D.W.; et al. Cancer disclosure in Japan: historical comparisons, current practices. *Soc. Sci. Med.* **1998**, *46*, 1151–1163.
15. Fielding, R.; Wong, L.; Ko, L. Strategies of information disclosure to Chinese cancer patients in an Asian community. *Psycho. Oncol.* **1998**, *7*, 240–251.
16. Orona, C.; Koenig, B.A.; Davis, A.J. Cultural aspects of nondisclosure. *Cambridge Q. Healthc Ethics* **1994**, *3*, 338–346.
17. Baile, W.F.; Lenzi, R.; Parker, P.A.; et al. Oncologists' attitudes toward and practices in giving bad news: an exploratory study. *J. Clin. Oncol.* **2002**, *20*, 2189–2196.
18. Elwyn, T.S.; Fetters, M.D.; Sasaki, H.; et al. Responsibility and cancer disclosure in Japan. *Soc. Sci. Med.* **2002**, *54*, 281–293.
19. Blackhall, L.J.; Murphy, S.T.; Frank, G.; et al. Ethnicity and attitudes toward patient autonomy. *JAMA*. **1995**, *274*, 820–825.
20. Seo, M.; Tamura, K.; Shiji, H.; et al. Telling the diagnosis to cancer patients in Japan: attitude and the perception of patients, physicians and nurses. *Palliat. Med.* **2000**, *14*, 105–110.
21. Phungrassami, T.; Sriplung, H.; Roka, A.; et al. Disclosure of a cancer diagnosis in Thai patients treated with radiotherapy. *Soc. Sci. Med.* **2003**, *57*, 1675–1682.
22. Hern, H.E.; Koenig, B.A.; Moore, L.J.; et al. The difference that culture can make in end-of-life decision making. *Cambridge Q. Healthc Ethics* **1998**, *7*, 27–40.
23. Lapine, A.; Wang, C.R.; Goldstein, M.; et al. When cultures clash: physician, patient, and family wishes in truth disclosure for dying patients. *J. Palliat. Med.* **2001**, *4*, 475–480.
24. Fowler, F.; Coppola, K.M.; Teno, J.M. Methodological challenges for measuring quality of care at the end of life. *J. Pain. Symptom. Manage.* **1999**, *17*, 114–119.
25. Tang, S.T.; Lee, S.Y.; Cancer diagnosis and prognosis in Taiwan: patient preferences versus experiences. *Psycho. Oncol.* **2004**, *13*, 1–13.
26. Feinstein, A.R.; Cicchetti, D.V. High agreement but low kappa: I. The problems of two paradoxes. *J. Clin. Epidemiol.* **1990**, *43*, 543–549.
27. Landis, J.R.; Koch, G.G. The measurement of observer agreement for categorical data. *Biometrics* **1977**, *33*, 159–174.
28. Caruso, A.; Francesco, B.; Pugliese, P.; et al. Information and awareness of diagnosis and progression of cancer in adult and elderly cancer patients. *Turrori.* **2000**, *86*, 199–203.
29. Gattellari, M.; Voigt, K.J.; Butow, P.N.; et al. When the treatment goal is not cure: are cancer patients equipped to make informed decisions? *J. Clin. Oncol.* **2002**, *20*, 503–513.
30. Christakis, N.A.; Lamont, E.B. Extent and determinants of error in doctors' prognoses in terminally ill patients: prospective cohort study. *BMJ* **2000**, *320*(7233), 469–72.
31. Hinton, J. The progress of awareness and acceptance of dying assessed in cancer patients and their caring relatives. *Palliat. Med.* **1999**, *13*, 19–35.
32. Estape, J.; Palombo, H.; Hernandez, E.; et al. Cancer diagnosis disclosure in a Spanish hospital. *Ann. Oncol.* **1992**, *3*, 451–454.
33. Pronzato, P.; Bertelli, G.; Losardo, P.; et al. What do advanced cancer patients know of their disease? A report from Italy. *Support Care Cancer* **1994**, *2*, 242–244.
34. Mystakidou, K.; Liossi, C.H.; Vlachos, L.; et al. Disclosure of diagnostic information to cancer patients in Greece. *Palliat. Med.* **1996**, *10*, 195–200.
35. Prigerson, H.G. Socialization to dying: social determinants of death acknowledgment and treatment among terminally ill geriatric patients. *J. Health Soc. Behav.* **1992**, *33*, 378–395.
36. Pullman, D. Dying with dignity and the death of dignity. *Health Law J.* **1996**, *4*, 197–219.
37. Chochinov, H.M.; Hack, T.; McClement, S.; et al. Dignity in the terminally ill: A developing empirical model. *Soc. Sci. Med.* **2002**, *54*, 433–443.
38. Benson, J.; Britten, N. Respecting the autonomy of cancer patients when talking with their families: qualitative analysis of semistructured interviews with patients. *Br. Med. J.* **1996**, *313*, 729–731.
39. Marwit, S.J.; Datson, S.L. Disclosure preferences about terminal illness: an examination of decision-related factors. *Death Stud.* **2002**, *26*, 1–20.
40. Yun, Y.H.; Lee, C.G.; Kim, S.; et al. The attitudes of cancer patients and their families toward the disclosure of terminal illness. *J. Clin. Oncol.* **2004**, *22*, 307–314.
41. Fallowfield, L.; Jenkins, V. Communicating sad, bad, and difficult news in medicine. *Lancet.* **2004**, *363*, 312–9.