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# Solving Family-related Barriers to Truthfulness in Cases of Terminal Cancer in Taiwan

## A Professional Perspective

**KEY WORDS**

Truthfulness
Terminal cancer
Palliative care

The study investigated the puzzling factors and solutions of family-related barriers to truthfulness with patients with terminal cancer through a nationwide survey conducted in Taiwan. Two-hundred twenty-nine valid questionnaires were retrieved (91.6%) from 250 palliative care workers at 15 Taiwan hospices. Most of the respondents were nursing staff (72.5%), and only 38 respondents were physicians (16.6%). Canonical correlation analysis was used to examine the association between the puzzling factors and solutions, which revealed that the value of the first variate was 0.39 ($P < .05$). Results showed that the puzzling factors of barriers and canonical loadings were families do not know how to tell the truth (.85), families believe it is unnecessary to tell aged patients the truth (.71), and patients can be happier without knowing the truth (.70). The valid solutions correlated significantly with the above puzzling factors and were ranked in the following order: communicate with and encourage families to accept patients' prognoses (.83), discuss the sickness gently with patients and determine what patients know (.76), and tell the families about the possible emotional reactions in patients and how to provide support (.72). In conclusion, for solving family-related barriers to truthfulness in cases of terminal cancer, the results suggest that health professionals communicate with families first and discuss the possible emotional reactions from patients, give patients enough time to reflect on their sicknesses and discuss further what patients have been told, and then disclose information based on patients' expectations and support them.

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# ■ Introduction

Many studies indicate that most patients with cancer patients to know the nature and prognosis of their diseases. However, only a small portion of patients actually obtains enough information as they wish. Truthfulness, or disclosure of information, has particularly become more puzzled when the patient's disease is incurable.[1-11] In many countries, especially in the East, families and patients keep the bad news mutually silence. Moreover, the families always request that medical professionals do not disclose the truth about the diagnoses and prognoses of the cancers to the patients. This situation makes patients unable to participate in numerous decisions about the treatment and care planning or exercise their right to choose, which inevitably affects the quality of care.[12-16]

The issue of truthfulness in terminal illness has also drawn attention in Japan. Aoki et al reported that the average length of admission before death was markedly shorter for patients who had been told the diagnosis or prognosis than for patients who had not.[17] On the other hand, telling patients with terminal cancer the truth about their diagnoses or prognoses is important for them to spend a fulfilling terminal stage.[17] Okazaki et al found that psychologic symptoms were observed less frequently in informed patients than they were in uninformed patients.[18] Seo et al indicated in their study that the majority of physicians and nurses believed that disclosing the diagnosis had a positive effect and should be promoted.[19] Cheng et al conducted a study in Taiwan that showed how awareness of the truth in cases of terminal cancer was significantly correlated to the mean scores of good death measurement.[20] However, Chiu et al found that the most frequent dilemmas encountered in a palliative care unit were place of care (33.3%) and truthfulness (32.1%), which puzzled the medical staff, families, and patients.[21] A multicenter study of palliative care workers by Chiu et al also showed that families' barriers to truthfulness in cases of terminal cancer was one of the most frequent puzzling issues encountered in the provision of palliative care.[14] Because the notions of philosophy and ethics may have varied meanings and relative values in different cultures, it is important to know the norms of truthfulness and mores within each particular culture. The study not only identified the puzzling factors of family-related barriers to truthfulness of the diagnosis of terminal cancer but also investigated the solutions to these barriers based on the experience and opinion of palliative care professionals. The results suggest improvement in truthfulness or disclosure of information of terminal cancer, which may promote the quality of care.

# ■ Methods

## Subjects

This study was conducted from May 1999 to February 2000. A semistructured questionnaire had been designed and distributed to the study sample, including 250 palliative care workers at 15 hospices in Taiwan. Two-hundred twenty-nine valid questionnaires (91.6%) were retrieved from the respondents at the 15 hospices, including 166 (72.5%) nurses, 38 (16.6%) physicians, and 25 other professionals (10.9%).

## Instrument

The design of the instrument was twofold. First, a lower structured questionnaire relating to the barriers of truthfulness from families was designed after a careful scrutiny of the literature in this area by the investigators. Twenty experienced workers were also asked to propose the possible reasons and solutions. These workers were composed of physicians, nurses, psychologists, social workers, and leaders of volunteers, all of whom were experienced in the care of patients with terminal cancer. In addition, the study also invited 3 bereaved families of patients with terminal cancer to provide their opinions about the content of items in the questionnaire for increased comprehensiveness. All items were grounded on the basis of real-life experiences of workers and families involved palliative care. To ensure high face validity, the items were reviewed again by all investigators and other workers in palliative care.

Second, jury validity by 6 experts was used to further confirm the items regarding the appropriateness and ease of application. Each item was evaluated on a scale of 1 (low) to 5 (high) for clarity and relevance to clinical practice. Those items with a rating of at least 4.5 for clarity and 4.5 for relevance to practice were selected for inclusion. This process resulted in the elimination of 3 items, thus yielding a final 29-item version measurement.

Finally, the instrument included: (1) demographic information about the respondents, including age, gender, experiences of palliative care, etc (n = 14 items); (2) the puzzling factors of the dilemma rating of the extent of influences for each item (1—no influence, 2—slight influence, 3—moderate influence, 4—severe influence, 5—extreme influence) (n = 7 items); and (3) the solutions to the dilemma and the strategies to solve the puzzling factors (n = 8 items). The respondents were asked to rate the extent of the usefulness (1—not useful, 2—only a little useful, 3—useful, 4—very useful, 5—definitely useful) and the frequencies of use (1—never used, 2—rarely used, 3—sometimes used, 4—often used, 5—always used). For the reliability, the Cronbach's alpha internal consistency reliability coefficients of puzzling factors and solutions were 0.82 and 0.86, respectively, for this study sample, which indicated good internal consistency.

## Statistical Analysis

Data management and statistical analysis were performed using the SAS statistical software. Frequency distributions were used to describe the demographic data and the distribution of each variable. Mean values and standard deviation were used to analyze the extent of each variable. Analysis of variance (ANOVA) and Scheffe's test were used to compare the group differences between demographic data and the puzzling factors or the valid solutions. A multivariate technique, referred to as the canonical correlation analysis, was then used to examine the association between the two sets of variables—that is, the

independent variables (7 puzzling factors) and the dependent variables (the extent of effect of the 8 solutions).

Canonical loadings measure the simple linear correlation between an originally observed variable in the independent or dependent set and the set's canonical variate. Canonical weights examine the magnitude of the canonical weight assigned to each variable in its canonical variate. Adequacy measures the amount of variation in each of the independent or dependent variables explained by the independent or dependent canonical variate, the amount of which is a simple average of the squared loadings. Explained variance (Canonical $R^2$) is the percentage of variance in the dependent canonical variate that can be explained by the independent canonical variate, the amount of which is the squared canonical correlation.[22] A $P$ value of less than .05 was considered statistically significant in this study.

# ■ Results

## Demographic Data

A total 229 out of 250 palliative care workers returned the questionnaire (response rate = 91.6%). Of these, 34 were male (14.8%) and 195 (85.2%) female, with a mean age of $31.10 \pm 8.05$ years (Table 1). Most of the respondents were nursing professionals (72.5%), and 38 (16.6%) of the respondents were physicians, with a mean professional experience of $22.48 \pm 20.14$ months. Only 15 respondents (6.5%) were not satisfied with their current work.

Concerning religious beliefs, 26.6% and 23.6% of the respondents were Buddhists and Taoists, respectively, and only 14.0% were Christians. Approximately two thirds of the respondents (61.2%) recognized the personal importance of religious belief.

| ※ Table 1 • Demographic Information of Respondents (n = 229) | | |
|---|---|---|
| Variables | No. | % |
| Sex | | |
| Male | 34 | 14.8 |
| Female | 195 | 85.2 |
| Age groups (mean = 31.10 y, SD = 8.05) | | |
| ≤ 25 | 59 | 25.8 |
| 26~35 | 120 | 52.4 |
| 36~45 | 33 | 14.4 |
| ≥ 46 | 17 | 7.4 |
| Professionals | | |
| Nurses | 166 | 72.5 |
| Physicians | 38 | 16.6 |
| Other professionals | 25 | 10.9 |
| Religions | | |
| Buddhist | 61 | 26.6 |
| Taoist | 54 | 23.6 |
| Christian | 32 | 14.0 |
| Catholic | 13 | 5.7 |
| Not specific | 57 | 24.9 |
| Others | 12 | 5.2 |
| Personal importance of religion | | |
| Very important | 41 | 17.9 |
| Important | 99 | 43.2 |
| Fair | 76 | 33.2 |
| Not important | 12 | 5.2 |
| Not at all | 1 | 0.4 |
| Experience of professionals, mo | | |
| ≤ 6 | 44 | 19.3 |
| 7~12 | 47 | 20.5 |
| 13~24 | 73 | 31.9 |
| 25~36 | 23 | 10.0 |
| ≥ 37 | 42 | 18.3 |
| Mean ± SD (22.48 ± 20.14) | | |
| Satisfactions to current works | | |
| Very satisfied | 13 | 5.7 |
| Satisfied | 99 | 43.3 |
| Fair | 102 | 44.5 |
| Unsatisfied | 14 | 6.1 |
| Very unsatisfied | 1 | 0.4 |

## Puzzling Factors and Solutions of the Family-related Barriers to Truthfulness

Regarding the extent of influence of puzzling factors toward the barriers, the mean values of each item were ranked as the family is unable to manage the patient's emotional reactions (mean ± SD, 3.94 ± 0.85), truthfulness of terminal cancer diagnosis means the announcement of medical failure and imminent death (3.92 ± 0.78), and patients will be sad and commit suicide (3.89 ± 0.98) (Table 2). With respect to valid solutions (Table 3), the most useful strategy proposed by the respondents was to discuss the sickness gently with patients and determine what the patients know (mean ± SD, 3.85 ± 0.70). However, this was only the second most commonly used method in clinical practice. The second and third valid solutions were to identify what patients and families know and find the appropriate time and person to give more information (3.79 ± 0.71) and to communicate with and encourage the family to accept the patient's prognosis (3.77 ± 0.72). On the other hand, the fourth valid strategy proposed was also the most commonly used method in clinical practice, which is to tell the families that most patients have actually known their prognosis and it will be better to disclose the truth (3.67 ± 0.71).

## Comparisons Between Demographic and Variables of Puzzling Factors and Solutions

The group differences between demographic characteristics and puzzling factors or solutions were computed and analyzed by ANOVA and Scheffé test. The results showed that gender and professional variables had significant differences in recognizing the extent of influences of puzzling factors. The results also showed that the perceptions of women and nursing staff regarding the extent of influence of "truthfulness means the announcement of medical failure and imminent death" was significantly higher than that perceived by men or physicians ($P < .01$ and $P < .05$, respectively).

With respect to the solutions, variables such as gender, age, personality, experiences of having a member with terminal cancer in the family in the last 3 years, and the satisfaction in current work had significant differences in proposing useful solutions. Persons who were male, optimistic in personality, and with no experience of having a terminal cancer in the family in the last 3 years perceived the effect of "explaining the benefits of truthfulness to families" higher than the recognition by women, pessimistic in personality, and with experiences of terminal cancer in the family ($P < .05$, $P < .05$, and $P < .05$, respectively). Persons younger than 24 years of age rated the effect of "informing the families that the patient has the right to know the truth" higher than those within the age group of 36 to 45 years ($P < .01$). Respondents with optimistic personalities claimed that it is more useful to "tell the family about the possible emotional reactions in patients and the way to support" than did those with pessimistic personalities ($P < .05$).

## The Association Between Variables of Puzzling Factors and Solutions

Canonical correlation analysis was used to examine the association between variables of puzzling factors and solutions. Of the initial variables, only the independent (puzzling factors) and dependent (solutions) variables that correlated significantly were retained for the canonical analysis. As seen in Table 4, only one canonical variate was found to be significant (canonical correlation = 0.39, $P < .05$). This first canonical variate was found for 7 puzzling factors (canonical loading > 0.3) and correlated with 7 valid solutions (canonical loading > 0.3), explaining 15.21% of the variance. The adequacy of the independent and dependent variables in the first canonical variate were 41.41% and 40.69%, respectively. The redundancy index for the independent and dependent variates, calculated as the adequacy times the canonical $R^2$, were 6.30 % and 6.19%, respectively.

The 7 puzzling factors (independent variables) and canonical loadings to the first canonical variate included families who do not know how to tell the patient the truth (0.85), the belief that it is unnecessary to tell aged patients the truth (0.71), the belief that patients can be happier without knowing the truth (0.70), families that are unable to manage patients' emotional reactions (0.63), the belief that patients will be sad and commit suicide (0.56), families that cannot accept the disease patients' prognoses (0.51), and the belief that truthfulness means the announcement of medical failure and imminent death (0.46). The correlated solutions (dependent variables) and canonical loadings in the first canonical variate included

| Table 2 • Professionals' Self-ratings of Puzzling Factors That Influence Truth Telling (n = 229) | |
|---|---|
| Puzzling Factors | Degree of Influences, Mean* ± SD |
| 1. The family is unable to manage patient's emotional reactions. | 3.94 ± 0.85 |
| 2. Truth telling of terminal cancer means the announcement of medical failure and imminent death. | 3.92 ± 0.78 |
| 3. Patients will be sad and commit suicide. | 3.89 ± 0.98 |
| 4. Families don't know how to tell patients the truth. | 3.74 ± 0.86 |
| 5. Patients can be happier without awareness of truth. | 3.70 ± 0.83 |
| 6. Unnecessary to tell the aged patients the truth. | 3.60 ± 0.97 |
| 7. Families can't accept the disease prognosis of patients. | 3.52 ± 0.95 |

*Range includes 1 to 5, with higher score indicating greater influence.

| Solutions | Degree of Effectiveness | | Frequency of Use | |
|---|---|---|---|---|
| | Mean ± SD | Rank | Mean ± SD | Rank |
| 1. To discuss the sickness gently with patients and determine what patients know | 3.85 ± 0.70 | 1 | 3.80 ± 0.82 | 2 |
| 2. To identify what patients and families know and find the appropriate time and person to give more information | 3.79 ± 0.71 | 2 | 3.78 ± 0.86 | 4 |
| 3. To communicate with and encourage families to accept patients' prognoses | 3.77 ± 0.72 | 3 | 3.79 ± 0.86 | 3 |
| 4. To tell families that most patients have actually known their prognoses and it will be better to disclose the truth | 3.67 ± 0.71 | 4 | 3.84 ± 0.82 | 1 |
| 5. To tell families about the possible emotional reactions in patients and the way to support | 3.56 ± 0.70 | 5 | 3.66 ± 0.82 | 6 |
| 6. To provide the help of psychologists or social workers | 3.51 ± 0.78 | 6 | 3.67 ± 0.90 | 5 |
| 7. To explain the benefits of truth telling to families | 3.29 ± 0.71 | 7 | 3.56 ± 0.93 | 7 |
| 8. To tell families that patients have the right to know | 3.14 ± 0.76 | 8 | 3.47 ± 0.96 | 8 |

communicate with and encourage families to accept the patients' prognoses (0.83), discuss the sickness gently with patients and determine what patients know (0.76), tell families about the possible emotional reactions in patients and how to support them (0.72), identify what patients and families know and find the appropriate time and person to give more information (0.65), tell families that most patients have actually known their prognosis (0.58), provide the help of psychologists or social workers (0.40), and explain the benefits of truthfulness (0.38). The results of canonical correlation analysis indicated that the more influential of those 7 puzzling factors are also the more effective of those 7 solutions.

Furthermore, canonical weights analysis showed that the extent of puzzling factors as a group was associated moderately strong with "families did not know how to tell patients the truth" (canonical weight, $r = 0.63$), "patients can be happier without awareness of truth" ($r = 0.37$), and "it is unnecessary to tell aged patients the truth" ($r = 0.34$). On the other hand, the variable solutions as a group were most strongly associated with "to communicate with and encourage the families to accept patients' prognosis" ($r = 0.59$), followed by "to tell families about the possible emotional reactions of patients and the way to support them" ($r = 0.43$) (Table 4).

Table 4 • Canonical Correlation Analysis to the Association Between Puzzling Factors and Solutions*

| | Canonical Loading | Canonical Weight |
|---|---|---|
| Puzzling factors (adequacy = 41.41%) | | |
| 1. Families don't know how to tell patients the truth | 0.85 | 0.63 |
| 2. Unnecessary to tell aged patients the truth | 0.71 | 0.34 |
| 3. Patients can be happier without awareness of truth | 0.70 | 0.37 |
| 4. Families are unable to manage patients' emotional reactions | 0.63 | 0.04 |
| 5. Patients will be sad and commit suicide | 0.56 | 0.06 |
| 6. Families can't accept the disease prognoses of patients | 0.51 | 0.14 |
| 7. Truth telling means the announcement of medical failure and imminent death | 0.46 | −0.38 |
| Solutions (adequacy = 40.69%) | | |
| 1. To communicate with and encourage families to accept patients' prognoses | 0.83 | 0.59 |
| 2. To discuss the sickness gently with patients and determine what patients know | 0.76 | 0.33 |
| 3. Tell families about the possible emotional reactions in patients and the way to support | 0.72 | 0.43 |
| 4. To identify what patients and families know and find the appropriate time and person to give more information | 0.65 | 0.03 |
| 5. To tell families that most patients have actually known their prognoses | 0.58 | 0.15 |
| 6. To provide the help by psychologists or social workers | 0.40 | −0.05 |
| 7. To explain the benefits of truth-telling to families | 0.38 | −0.22 |

*Canonical correlation = 0.39.

# ■ Discussion

This study used canonical correlation analysis to examine the association between the puzzling factors and the solutions of family-related barriers to truthfulness of a terminal cancer diagnosis from the perspective of professionals. The retained reason that had the highest influence to the barriers was "families don't know how to tell patients the truth." In the Eastern culture, it is common for health professionals not to disclose the true diagnosis of disease, especially to a patient with terminal cancer, on the basis of non-maleficence. The decision whether to disclose the cancer diagnosis and prognosis is usually left to the family. Furthermore, families also always ask health providers not to disclose the truth to the patients. However, mutual silence prevails because both the families and the patients are unwilling to hurt each other and lack the knowledge of how to communicate with each other, despite that families may understand the benefits of telling the truth.

In current circumstances, families can only encourage patients with some phrases such as "go-go," "you will become better," or "don't give up," which circumvent further discussions about their illness. This situation usually makes patients overestimate their survival time, develop unrealistic expectations, and, consequently, have conflicts over therapeutic strategies with health professionals. Without the chance of discussing the prognosis of the disease, patients were unable to participate in treatment decisions and care planning or to prepare their futures. That families did not know how to tell the patients also made it impossible for patients to appreciate the dedicated care of health professionals and puzzled and distressed these caregivers. Thus, the question of helping families cope with the emotional burden of communicating with their ill relative is an important matter in terminal care.

The problem with "truthfulness means the announcement of medical failure and imminent death" was that it was strongly associated with the extent of puzzling factors as a group, particularly for women and nursing staff. This situation might be due nursing staff spending more time taking care of patients and families, which made them more sensitive to these families' concerns. Meanwhile, families also usually believed that the patients would be unhappy and have more suffering after disclosure of such information. Moreover, the possibility that patients might commit suicide was another factor about which families worried. However, in studies conducted by Aoki and Cheng,[17,20] both of their results showed that informing patients with terminal cancer about the truth of their diagnoses or prognoses might help them have a fulfilling terminal stage and higher quality of death. Continuing education and better communication with families based on study evidences about truthfulness is important in solving this difficult problem.

With respect to the solutions to family-related barriers of truthfulness, "to communicate with and encourage families to accept the truth" was associated most strongly with the extent of effect of solutions variables as a group. It was followed by "to tell families about the possible emotional reactions and the way to support." From these findings, we find that palliative care workers recognize the importance of communicating with the families, supporting them and further persuading them to accept the patients' prognoses, rather than only educating the families regarding "the benefits of truth telling" or that "patients have rights to know the truth" in this culture. Moreover, health professionals may tell the families the possible emotional reactions from patients after disclosing the truth. In clinical experience, most of the patients would be upset initially. However, majority of them would be able to cope with the truth moderately well several days later. In some countries such as Japan, there are proposed guidelines for truthfulness, which will hopefully allow the bad news to be told to patients in a supportive way.[15] Palliative care workers explain to families the usual emotional reactions of patients and the ways to support these, thereby decreasing families' anxieties and increasing the motivation of families to tell their patients the truth.

The third valid solution of canonical correlation analysis was to discuss the sickness gently with patients and determine what patients know. After communicating with families and supporting them to accept the patients' prognoses, it is important in the next step to determine what patients actually know. Palliative care workers may discuss the sickness with patients during the process of care so that patients may express naturally what they already know and what they hope to do about the disclosure of the truth. "What do you think about your sickness?" and "Would you like to have more information about your illness?" are questions that have been recently promoted at the Taiwanese hospices. The first question usually gives palliative care workers the cues on how to solve the difficult problems smoothly. The second question can make patients' wishes (prefer to or prefer not to be informed) clear. Some patients did not want to know more information, and their autonomy should be respected.[23]

Despite that the study was conducted in hospices and palliative care units, the dilemma of truthfulness about a terminal cancer diagnosis was also believed to be frequently encountered in oncology care providers. Health professionals in general practice or in oncology units find it too uncomfortable to tell patients that they cannot effectively fight their cancer because it means that clinicians have failed. They are often faced with the dilemma regarding their ethical roles of beneficence and their obligations to respect the right of patient autonomy.[24] Special courses and workshops in this area pertaining to truthfulness should be provided by medical and nursing schools and hospitals, particularly training in ethical roles and communication skills that can reduce the barriers and enhance the health professionals' abilities and effectiveness in providing patients and their families with adequate information per patients' wishes.[25] Meanwhile, if health professionals in general practice and in oncology units can confront the issues of truthfulness and effectively provide adequate information early, the dilemma of disclosing information will be lessened in hospices, which will then be able to promote quality of care. On the other hand, it will be also necessary to provide public discussions through mass media or conferences for the people to promote public concern and awareness about the issues surrounding disclosure of bad news. These endeavors will provide people with more knowledge and skills in truthfulness and naturally alleviate some barriers to it.

There are no formal guidelines proposed in Taiwan, and telling patients the truth about their illnesses is legally complex.

However, the National Death Act in Taiwan was legalized in 2000 to protect the rights of the terminally ill and includes a regulation that requests health professionals to take the responsibility of disclosing the adequate information per the patients' wishes.[26] In this case, the results of this study indicates some helpful methods for oncology and palliative care providers to handle this obligatory and difficult task smoothly.

Finally, it is worthwhile to mention the discrepancy between the most valid solutions proposed and the methods most frequently used in clinical practice. It is probably a myth that oncology and palliative care providers usually respect the wishes of families rather than those of patients, which is believed to conflict with the goals of palliative care. With respect to the real situation of palliative care practice, health professionals can only act as the bridge between patients and their families, if both know the prognosis of the disease. Nevertheless, if patients do not know the truth due to inadequate information, they may still gradually become aware of the severity of the illness due to the deterioration of their physical functions. In this case, the tasks for health professionals are to continue compassionate care and discuss the sickness with patients gently in the process of care. Aside from relieving the distressing symptoms, the other important tasks of health professionals include making endeavors to strengthen patients' psychospiritual power and assisting in better preparations for the future. These endeavors make the patients focus on promoting life quality, which should be a constant part in every effort to disclose the diagnosis or outcome of the cancer.

Some limitations should be mentioned in relation to this study. First, the respondents involved in this study are not representative of the healthcare providers in oncology care units and thus generalization of the results should be of some concern. Second, the study was aimed only at investigating the barriers for families. In Confucian culture, which predominates in the specific area of the study, the family's will is always respected rather than that of the individual, and patients with terminal cancer might agree with the family's policy of not breaking the bad news. Despite the Confucian culture, the patient's concerns should be further identified and promoted as a more appropriate care plan for this vulnerable group.

For solving the family-related barriers to the truthfulness of disclosing the diagnosis of terminal cancer, the study conclusively suggests that health professionals: (1) communicate with families for the acceptance of patients' outcomes, (2) discuss with the families regarding possible emotional reactions and the coping mechanisms, (3) give patients enough time to reflect on their sickness and further discuss what patients have been told about the sickness, and (4) give more information based on patients' expectations and support them compassionately. Meanwhile, training courses for professionals on the ethical roles, communication skills, and public education to promote the awareness and concerns of people regarding this issue remain worthwhile efforts.

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