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Why Taiwanese hospice patients want to stay in hospital: health-care professionals' beliefs and solutions

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Abstract Patient-related barriers and their solution in the planning of discharge to palliative home care were investigated through a nationwide survey conducted in Taiwan. Of 250 questionnaires sent to palliative care workers at 15 hospices in Taiwan, 229 valid questionnaires (91.6%) were retrieved. Most of the respondents were nursing staff (72.5%) while only 38 were physicians (16.6%). Canonical correlation analysis was used to examine the association between the barriers and solutions, and revealed that the value of the first variate was 0.49 ($P < 0.05$). The barriers and canonical loadings were: unable to manage emergent medical conditions (0.83), the quality of care in the hospital is better (0.74), and insufficient number of caregivers (0.72). The effective solutions that correlated significantly with the above factors were ranked as: to reassure the patient about the possibility of smooth readmission (0.84), to arrange palliative home care programs (0.68), and to educate family members on taking care of the patient

at home (0.64). In conclusion, to solve patient-related barriers in the planning of the discharge of patients with terminal cancer, the results suggest that (1) health professionals involved in the care of patients with terminal cancer should have adequate knowledge of palliative care, particularly communication skills, (2) an effective referral system among general or oncology and palliative care units should be established, (3) inpatient care facilities and home-care programs should be provided, and (4) patients and families should be educated as to what may happen and how to manage these conditions at home and should be assured of the availability of medical help.

Keywords Palliative home care · Terminal cancer · Barrier

Introduction

Where people die has changed during the 20th century. In the early 1900s in the US it was common for someone to die at home, while by the 1980s, nearly 80% of deaths occurred in institutions [1, 3]. Most Americans want to die at home if they are terminally ill [22, 25]. Yet most people suffering from cancer and other chronic conditions

die in acute-care hospitals or nursing homes [9, 13, 14]. In the UK, the percentage of people with cancer who die at home declined from 37% in 1965 to 27% in 1987 [25]. Only 14% of people in South Australia died at home in 1987 [18, 19]. In oriental countries, the same trend has been noted: the number of people dying in hospitals has increased over several decades. Currently in Japan, about 80% of people die in hospitals while only 20% did so

right after the Second World War [21]. A similar trend has occurred in Taiwan but with some delay: in 2001 hospital and home deaths accounted for 35% and 57.6%, respectively, while in 1984 equivalent figures were 23.5% and 62.0%, respectively [10, 11].

However, is this what people in these countries want? Or is it a compromise due to the deficiencies of medical care systems or the limitations of social support? McWhinney et al. found that although 60% of patients wish to die at home, half of them are not accorded their wish [20]. A community study by Chiu and Ohi has shown that only 44.6% of Taiwanese subjects would choose home as the preferred place for terminal care. Yet 59.4% of those respondents who originally chose hospital, would change their mind and choose home as the preferred place for terminal care if home palliative care were available. In that study, it also found that 80% of respondents in Taiwan and 58.9% in Japan hoped to die at home [5]. A study by Chiu in 1996 showed that of 329 patients with terminal cancer in a palliative care unit, 43.1% of respondents preferred to die in hospital and 56.9% would rather die at home. Of these, 59.1% eventually died in the hospital and 40.9% at home. Many of those who died at home were actually kept alive just long enough to transfer from hospital to home, and then died soon afterwards [4].

The goals of palliative care are to achieve the best quality of life and a good death for patients. Saunders wrote that the philosophy of terminal cancer care is that "patients should end their lives in the place most appropriate to them and their families" [24]. A good death is defined as "in general accord with patients' and families' wishes" [3]. It is important to investigate the reasons for the discrepancy between the preference to have terminal care then die at home and the actual place of dying, and determine strategies to resolve this discrepancy.

In practice, the transfer of patients from institutions to their home for a palliative home-care program is difficult in Taiwan. Chiu et al. found that the most frequent dilemma encountered in a palliative care unit is the place of care (33.3%), which presented a problem for the medical staff, families, and patients [7]. A multicenter study of palliative care workers by Chiu et al. also showed that discharge planning for terminal cancer patients is one of the ten most frequent difficult issues encountered in the provision of palliative care in Taiwan [6]. Since philosophical and ethical considerations may vary in their meaning and relative value between different cultures, it is important to know about the barriers to discharge planning for palliative home care and the mores within each particular culture. This study not only identified the barriers to transferring patients with terminal cancer to palliative home care but also investigated the solutions to these barriers based on the experience and opinion of palliative care professionals. The results suggest the importance of improving the discharge to palliative home

care and of dying at home in terminal cancer, which may promote the quality of terminal care.

Methods

Subjects

This study involving health professionals in all hospices in Taiwan was conducted during the period of 1999 to 2000. A semistructured questionnaire was designed and sent to the study sample, which included 250 palliative care workers at 15 hospices in Taiwan; 229 valid questionnaires (91.6%) were retrieved. The respondents included 166 nurses (72.5%), 38 physicians (16.6%), and 25 other allied medical professionals (10.9%).

Instrument

The design of the instrument was twofold. First, a lower structured questionnaire relating to patient-related barriers to discharge planning was designed after a careful scrutiny of the literature in this area by the investigators. A group of 20 experienced workers were also asked to propose possible reasons and solutions. These workers comprised 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 three bereaved families of terminal cancer patients to provide their opinion about the content of the items in the questionnaire in order to increase comprehensibility. All of the items were grounded in the real life experiences of workers and families involved in palliative care. To ensure high face validity, the items were reviewed again by all the investigators and other workers in palliative care.

Second, jury validation by six experts was used to further confirm the items regarding 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 at least 4.5 for clarity and 4.5 for relevance to practice were selected for inclusion. This process resulted in the elimination of three items, thus yielding a final 29-item version of the instrument.

Finally, the instrument included: (1) demographic information about the respondents, including age, gender, and experiences of palliative care (14 items); (2) the barriers to patient transfer rating the extent of influence of each item (1 no influence, 2 slight influence, 3 moderate influence, 4 severe influence, 5 extreme influence) (8 items); and (3) solutions to and strategies in solving the barriers (7 items). The respondents were asked to rate the usefulness (1 not useful, 2 only a little useful, 3 useful, 4 very useful, 5 definitely useful) and frequency of utilization (1 never used, 2 rarely used, 3 sometimes used, 4 often used, 5 always used) of the solutions. Cronbach's alpha internal consistency reliability coefficients of barriers and solutions were 0.83 and 0.76, respectively, for this study sample, which indicated good internal consistency.

Statistical analysis

Data management and statistical analysis were performed using 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. ANOVA and Scheffé's test were used to compare the group differences between demographic data and the barrier factors or the valid solutions. A multivariate technique, canonical correlation analysis, was then used to examine the association between the two sets of variables—the independent variables (eight

barriers) and the dependent variables (the effectiveness of the seven 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 weight assigned to each variable as its canonical variate. Adequacy is a measure of 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 loading [15]. *P* values less than 0.05 were 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 (14.8%) were male and 195 (85.2%) female, with a mean age of 31.10±8.05 years (Table 1). Most of the respondents were

Table 1 Demographic information of the respondents (n=229)

Variable	No.	%
Sex		
Male	34	14.8
Female	195	85.2
Age groups (years) (mean±SD 31.10±8.05)		
≤25	59	25.8
26–35	120	52.4
36–45	33	14.4
≥46	17	7.4
Professions		
Nurses	166	72.5
Physicians	38	16.6
Other	25	10.9
Religions		
Buddhist	61	26.6
Taoist	54	23.6
Christian	32	14.0
Catholic	13	5.7
Not specified	57	24.9
Other	12	5.2
Personal importance of religion		
Very important	41	17.9
Important	99	43.2
Fairly important	76	33.2
Not important	12	5.2
Not at all	1	0.4
Experience of professionals (months) (mean±SD 22.48±20.14)		
≤6	44	19.3
7–12	47	20.5
13–24	73	31.9
25–36	23	10.0
≥37	42	18.3
Satisfaction with current work		
Very satisfied	13	5.7
Satisfied	99	43.3
Fairly satisfied	102	44.5
Unsatisfied	14	6.1
Very unsatisfied	1	0.4

Table 2 Self-ratings of professionals regarding barriers that influence discharge planning (n=229)

Barrier	Degree of Influence	
	Mean ^a	SD
1. Unable to manage the emergent medical conditions	4.10	0.79
2. Feeling safety in hospital	3.92	0.82
3. Insufficient number of caregivers	3.87	0.87
4. Quality of care in hospital is better	3.66	0.85
5. Afraid of the difficulties of readmission	3.41	1.10
6. More comfortable and convenient in the hospital	3.29	0.94
7. Poor home environment for care	3.19	0.95
8. Having more concern from families in the hospital	2.81	0.87

^a Range 1 to 5, with higher score indicating greater influence

nursing professionals (72.5%), while 38 (16.6%) were physicians, with a mean professional experience of 22.48±20.14 months. Only 15 respondents (6.5%) were not satisfied with their current work.

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

Barriers and solutions in discharge planning

Regarding the extent of the influence of barriers in discharge planning, the mean values of each item were ranked as: unable to manage the emergent medical conditions at home (mean±SD, 4.10±0.79), feeling more safety in hospital (3.92±0.82), and insufficient number of caregivers at home (3.87±0.87) (Table 2). With respect to effective solutions (Table 3), the most useful strategy proposed by the respondents was to arrange palliative home-care programs (3.82±0.86). However, this was only the second most commonly used method in clinical practice. The second solutions were to ensure the possibility of smooth readmission (3.69±0.93). On the other hand, the third effective strategy proposed was also the most commonly used method in clinical practice, which is to educate the family members on how to care for the patient (3.67±0.74).

Comparisons between demographic characteristics and variables in barriers and solutions

The group differences between demographic characteristics and barriers or solutions were computed and analyzed by ANOVA and Scheffé's test. The length of the respondent's experience in hospice care, the type of hospital to which the respondent's hospice belonged, and profes-

Table 3 Self-ratings of professionals regarding solutions to the barriers to discharge planning, degree of effectiveness, and frequency of use

Solutions	Degree of effective ness		Rank	Frequency of use		Rank
	Mean	SD		Mean	SD	
1. To arrange palliative home care programs	3.82	0.86	1	3.88	1.00	2
2. To assure the possibility of smooth readmission	3.69	0.93	2	3.79	1.13	4
3. To educate the family members how to care for patients	3.67	0.74	3	4.07	0.77	1
4. To explain the goals of inpatient care	3.39	0.77	4	3.87	0.84	3
5. To tell the patients it will be more comfortable at home	3.24	0.70	5	3.74	0.81	5
6. To find care facilities such as caregivers or nursing home	3.10	0.81	6	2.97	0.96	6
7. To explain that many patients with distress are waiting for admission	2.66	0.86	7	2.89	1.18	7

Table 4 Canonical correlation analysis of the association between barriers and solutions in discharge planning

	Canonical loading	Canonical weight
Barriers (adequacy 41.23%)		
1. Unable to manage the emergent medical conditions	0.83	0.45
2. Quality of care in hospital is better	0.74	0.38
3. Insufficient number of caregivers	0.72	0.44
4. Feeling safety in hospital	0.69	0.01
5. More comfortable and convenient in the hospital	0.54	0.01
6. Afraid of the difficulties of readmission	0.46	0.06
7. Having more concern from families in the hospital	0.39	0.15
Solutions (Adequacy=34.36%)		
1. To assure the possibility of smooth readmission	0.84	0.65
2. To arrange palliative home care programs	0.68	0.21
3. To educate the family members how to care for patients	0.64	0.36
4. To find care facilities such as caregivers or nursing home	0.43	0.18
5. To explain the goals of inpatient care	0.42	-0.05
6. To tell the patients it will be more comfortable at home	0.35	0.02

Canonical correlation 0.49

sional variables were significantly associated with the respondent's opinion of the degree of influence of each barrier. Respondents with a longer experience in hospice care perceived the degree of influence of "insufficient number of caregivers" to be significantly greater than did those with a shorter experience ($P<0.05$). Furthermore, other professionals (such as social workers and chaplains) and staff working in larger hospitals (such as university hospitals) perceived the degree of influence of "better quality of care in hospital" to be significantly greater than did physicians or nurses and those in smaller hospitals (such as community hospitals) ($P<0.05$, $P<0.05$, and $P<0.05$, respectively).

With respect to the solutions, variables such as the respondent's experience of having a family member with terminal cancer during the previous 3 years and the type of hospital, as well as professional variables, were significantly associated with proposing useful solutions. Staff who had no experience of having a family member with terminal cancer during the last 3 years perceived the effect of "arranging palliative home-care programs" to be greater than did staff with such an experience even though they did not directly care for the terminally ill family member ($P<0.01$). Staff working in the largest hospitals

perceived the effect of "ensuring the possibility of smooth readmission" to be greater than did staff working in smaller hospitals ($P<0.05$). Physicians rated "transfer to other care facilities such as nursing homes" more highly than nurses ($P<0.05$).

The association between variables in barriers and solutions

Canonical correlation analysis was used to examine the association between variables in barriers and solutions. Of the initial variables, only the independent (barriers) 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, $P<0.05$). This first canonical variate was found for seven barriers (canonical loading >0.3), and correlated with six effective solutions (canonical loading >0.3), explaining 24.01% of the variance. The adequacy of the independent and dependent variables in the first canonical variate were 41.23% and 34.36%, respectively.

The seven barriers (independent variables) and canonical loadings to the first canonical variate included: “unable to manage the emergent medical conditions” (0.83), “quality of care in hospital is better” (0.74), “insufficient number of caregivers” (0.72), “feeling of safety in hospital” (0.69), “more comfortable and convenient in hospital” (0.54), “afraid of the difficulties of readmission” (0.46), and “having more concern from families in hospital” (0.39). The correlated solutions (dependent variables) and canonical loadings in the first canonical variate included: “to ensure the possibility of smooth readmission” (0.83), “to arrange palliative home-care programs” (0.76), “to educate family members on caring for the patient” (0.72), “to find care facilities such as caregivers or nursing home” (0.65), “to explain the goals of inpatient care” (0.58), and “to tell the patient it will be more comfortable at home” (0.38). The results of canonical correlation analysis indicated that the more the influence in the seven barriers, the more effective the six solutions.

Furthermore, canonical weights analysis showed that the extent of barriers as a group was associated moderately strongly with “unable to manage the emergent medical conditions” (canonical weight, $r=0.45$), “insufficient number of caregivers” ($r=0.44$), and “quality of care in hospital is better” ($r=0.38$). On the other hand, the variable solutions as a group were most strongly associated with “to ensure the possibility of smooth readmission” ($r=0.65$), followed by “to educate family members on caring for the patient” ($r=0.36$) (Table 4).

Discussion

This study used canonical correlation analysis to examine the association between barriers and solutions to the dilemma of palliative home care for terminal cancer patients from the perspective of professionals. The retained barrier that had the highest influence in the dilemma was “unable to manage the emergent medical conditions at home”. This barrier has been recognized to be a common problem that influences the willingness of both patients and families to accept discharge planning from hospital to home [8, 12, 17]. The medical emergencies encountered commonly in palliative care patients include the sudden onset of severe pain, dyspnea, massive hemorrhage, and fever, which inevitably make the patients and their families feel anxious and suffer great distress [12]. The majority of cancer patients with pain can have their pain relieved in hospital after an active total care based on guidelines proposed by WHO. However, it is common to have breakthrough pain or dose-related pain occurring due to deterioration of the illness, which necessitates titration of the dosage of analgesics regularly. Inevitably, this influences the willingness of the patient to be discharged home. Some medications used to control cancer pain are administered via the parenteral route, which

families find difficult to use. In this case, we usually use the subcutaneous route instead of the intravenous route and educate families on how to use this method at home.

Terminal dyspnea, which is usually difficult to control well and severely hampers the quality of life of patients, is also an important factor that influences the possibility of discharge. The management of dyspnea in terminal cancer includes pharmacological and nonpharmacological treatment, such as chest care and oxygen use. The need for staff and equipment make discharge planning burdensome. Massive hemorrhage commonly occurs in patients with head and neck cancer, and is noted to be of higher prevalence in Taiwan [7]. Patients and families always fear the possibility of hemorrhage at home, which usually makes discharge home almost impossible. With regard to fever, this vulnerable group of patients very easily become infected due to their immunocompromised condition. The assessment of fever and the use of antimicrobial therapy, often used via the intravenous route and at regular intervals, increases the likelihood of staying in hospital. Aside from the above distressing symptoms, some medical conditions also make discharge planning very difficult. These include such issues as artificial nutrition and hydration in a patient with malignant bowel obstruction, and the use of agents to decrease the intracranial pressure due to brain metastases.

Concerning the emergent medical conditions related to barriers to discharge planning, it is not impossible to provide good care and resolve these barriers. Education of patients and families on proper care at home, providing palliative home care, referring to community medical professionals, and allocating resources of social services are helpful in arranging discharge. However, inadequate training in palliative care and lack of experience in caring for terminally ill patients by community medical professionals make community care for these terminally patients very difficult in present-day Taiwan [17]. Therefore, in the study many patients and families, and even the medical professionals, believed that the quality of care in hospital is better.

The barrier “insufficient number of caregivers” was strongly associated with the extent of the barriers as a group, particularly among the senior staff. This situation might have been due to the fact that the senior staff had more experience in caring for patients and families, which made them more sensitive to patients’ concerns concerning the burden on their family. A comparative study of attitudes in Taiwan and Japan indicated 76% of the population in Japan and 100% of the population in Taiwan opt for hospital as their place of terminal care because they did not want to increase the burden on their family [5]. Therefore, it would be worthwhile further investigating a way to resolve these barriers. In clinical experience, a good explanation to patients and their families about the nature of the illness and possible complications, and assistance to the families in arranging

carers for the patients can relieve patients' and families' anxiety and make discharge planning easier.

With respect to the solutions to patient-related barriers to discharge planning, "to ensure the possibility of smooth readmission" was associated most strongly with the effectiveness of the solutions as a group. From this finding, it appears that palliative care workers acknowledge the importance of getting immediate medical help for the patients. Clinically, we recognize that when the patient's illness becomes unresponsive to curative treatment in a cancer ward, he/she is often recognized as a medical failure and usually has to face the issue of discharge, which induces a feeling of abandonment in the patient. When terminally ill patients are readmitted to hospital from home, they may be kept in the emergency room due to the lower priority given to admission to a cancer ward. Such an unpleasant experience would make these patients unwilling to be discharged again and they hope to stay in the hospital until their death. A patient's unwillingness to be discharged might also be due to reasons such as an ineffective referral system or poor knowledge of patients or families about hospice care [27]. On the other hand, in oriental culture, it is common practice not to disclose the truth of illness especially to a terminally ill cancer patient on the basis of non-maleficence. With this cultural background, it is uncommon for medical staff in cancer wards to explain the indications for hospice care, and this makes it difficult for families to make a decision for referral to hospice care.

Another effective solution proposed is to arrange palliative home care for terminally ill patients. Previous studies have shown that among many patients and families who request home visits, the quality of palliative care in terms of home visits regardless of the number of home visits, especially for the dying, continues to fall [2, 16, 26]. In clinical practice, informing the patient that there is a palliative care program available would relieve the patient's anxiety and really help the process of discharge planning. Over the last decade, hospice and palliative care services have expanded in Taiwan, and there were 20 inpatient services and 43 home palliative care programs in 2002. However, almost all of these services are currently limited in the urban area.

The third effective solution from the canonical correlation analysis was "to educate families on how to care for patients at home". The higher prevalence of symptoms and rapid deterioration of the physical condition of patients with terminal cancer make the patients and their families feel uncertain as to the future and stresses the inevitability of death. Medical staff should explain fully the possible conditions at home and educate family caregivers on how to give medication properly and to provide good physical care. Meanwhile, it is necessary to explain the need for caregivers and help families arrange an appropriate schedule for the attendance of caregivers. Education for the care of the dying is also very important,

since the symptoms of dying, such as respiratory distress and consciousness disturbance, will usually make family caregivers concerned leading them to hurriedly deliver the patient to hospital again. In such cases, it is common practice for emergency physicians to conduct "first aid" using medical life-support systems, if there is no informed consent from the patient. Where the patient's condition is stabilized, family members may recall that the patient had previously expressed the wish to forego cardiopulmonary resuscitation, or they may acknowledge that cardiopulmonary resuscitation would only make the patient suffer. The discouraging result, however, is that emergency doctors are unwilling to withdraw futile life support such as cardiopulmonary resuscitation. When such an ethical dilemma occurs, dying at home becomes impossible. Therefore, advance care planning in education for the care of the dying is an important task in discharge planning and palliative home care.

In this study, the method of "help to find care facilities such as nursing home" was also significantly associated with the extent of solutions as a group, particularly that of the physician. This finding might indicate that nursing staff, rather than physicians, emphasize the quality of care and are more sensitive to a patient's wish to go home for the last days of life. Although about 20% of respondents in a Taiwanese community study chose the nursing home as the preferred place of terminal care, most of them preferred to go back home for their death [5]. Actually, improving the environment of houses and promoting the ability of care at home can increase the possibility of home palliative care and dying peacefully at home, rather than actually being kept alive just long enough to transfer from hospital or nursing institution to home, then to die soon afterwards.

Finally, "to explain that many distressed patients are awaiting admission" was not included in the correlated solutions of the first canonical correlation. From this finding, palliative care workers recognize the importance of confirming the accessibility of medical help, increasing the number of caregivers, rather than persuading patients or families by moral reasons alone.

Despite the fact that the study was conducted in hospices and palliative care units, dilemmas involved in discharge planning for terminal cancer were also believed to be frequently encountered by oncology care providers. Health professionals in general or in oncology units usually find it uncomfortable and difficult to arrange a discharge plan for their patients, whose illness is already unresponsive to curative treatment. They are often faced with a dilemma regarding their ethical role of beneficence and their obligation to respect the right of patient autonomy. Special courses and workshops pertaining to discharge planning should be provided by hospitals and medical and nursing schools, particularly the training in ethical roles and communication skills. Communication relating to the transfer and cooperative care of terminally

ill patients among staff in general and those of oncology and hospice units is also important. Such communication can reduce the barriers and enhance the health professional's ability and effectiveness in providing patients and their families with comprehensive information as to the patient's wishes [23], and solving the patient's concerns in advance care planning, including discharge from hospital to home. Meanwhile, if health professionals in general and in oncology units can confront the issues of truth-telling and effectively provide adequate information earlier, dilemmas in discharge planning will become less frequently encountered in hospices, which will then be able to promote quality of care.

Finally, it is worth mentioning the discrepancy between the most effective solutions proposed (to arrange palliative home care programs) and the methods most frequently used in clinical practice (to educate family members how to care for patients). It is probably a myth that palliative care providers usually respect the concerns of families rather than those of patients in local cultural practice, which is believed to be in conflict with the goals of palliative care.

Certain caveats should be mentioned in relation to this study. First, the respondents were not representative of the health-care providers in oncology care units and thus the generalizability of the results is of some concern. Second, the study was only aimed at investigating the barriers from patients. In Confucian culture, 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 being discharged home. Concerns from the perspective of the family should be further identified.

Third, health-care professionals often do not know fully what patients and families want and need. It may be more effective to go to patients and families directly to let them speak for themselves. However, patients and their families each have their own wishes and concerns, but mutual communication is lacking with this cultural background. The health-care professionals involved in the care of patients and their families usually act as the bridge, and are in an ideal position to clarify both patients' and families' concerns and their conflicts.

For solving the patient-related barriers to discharge planning in terminal cancer, the study conclusively suggests that: (1) health professionals involved in end-of-life care should have adequate palliative care knowledge, particularly communication skills, which are helpful in providing more information to patients and families for their advance care planning; (2) an effective referral system among general or oncology and palliative care units, between inpatient care facilities and home care programs, and between hospitals and community care needs to be established; and (3) continuous education of patients and families as to what may happen and how to cope with these eventualities at home, and to assure them of the availability of medical help should be provided. Enhancement of the abilities of community health professionals in terminal care is also worthwhile.

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References

1. Brock DB, Foley DJ (1998) Demography and epidemiology of dying in the US with emphasis on deaths of older persons. *Hospice J* 13:49–60
2. Cartwright A (1990) The role of the general practitioner in caring for people in the last year of their lives. King's Fund, London
3. Cassel CK, Field MJ (1997) *Approaching death: improving care at the end of life*. National Academy Press, Washington DC
4. Chiu TY (1996) Annual Report of Palliative Care of National Taiwan University Hospital. National Taiwan University Hospital, Taipei
5. Chiu TY, Ohi G (1995) The attitudes toward terminal care in rural communities in Taiwan and Japan: a comparative study. Unpublished master's thesis. University of Tokyo, Tokyo, Japan
6. Chiu TY, Hu WY, Tsay FC, Chou LL, Yao CA, Chen CY (1998) Ethical dilemmas in palliative care: a multi-center study. *Formos J Med* 2:633–640
7. Chiu TY, Hu WY, Cheng SY, Chen CY (2000) Ethical dilemmas in palliative care: a study in Taiwan. *J Med Ethics* 26:353–357
8. Chiu TY, Hu WY, Chen CY (2000) Prevalence and severity of symptoms in terminal cancer patients: a study in Taiwan. *Support Care Cancer* 8:311–313
9. Christakis NA (1998) Predicting patient survival before and after hospice enrollment. *Hospice J* 13:71–87
10. Department of Health, The Executive Yuan (1975) Vital statistics, Republic of China, 1974
11. Department of Health, The Executive Yuan (2002) Vital statistics, Republic of China, 2001
12. Finlay I (1996) Difficult decisions in palliative care. *Br J Hosp Med* 56:264–267
13. Fried TR, van Doorn C, O'Leary JR, Tinetti ME, Drickamer MA (1999) Older persons' preferences for site of terminal care. *Ann Intern Med* 131:109–112
14. Gilbar O, Steiner M (1996) When death comes: where should patients die? *Hospice J* 11:31–48
15. Hair JF, Anderson RE, Tatham RL, Black WC (1998) *Multivariate data analysis*, 5th edn. Prentice-Hall, New Jersey, pp 442–465
16. Hu WY, Chiu TY, Chuang RB, Chen CY, Chen YC, Dai YT (1999) The needs and satisfaction of main family caregivers in domiciliary palliative care. *Formos J Med* 3:527–537

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17. Hu WY, Chiu TY, Dai YT, Chang M, Jaing TH, Chen CY (2003) Nurses' willingness and predictors of the willingness to provide palliative care in rural community of Taiwan. *J Pain Symptom Manage* 26:760–768
 18. Hunt RW, Bond MJ, Groth RK, King PM (1991) Place of death in South Australia. Patterns from 1910 to 1987. *Med J Aust* 155:549–553
 19. Hunt R, Bonett A, Roder D (1993) Trends in the terminal care of cancer patients: South Australia, 1981–1990. *Aust N Z J Med* 23:245–251
 20. McWhinney IR, Bass MJ, Orr V (1995) Factors associated with location of death (home or hospital) of patients referred to a palliative care team. *CMAJ* 152:361–367
 21. Ministry of Health Welfare (MHW) (1994) Kokumin Eisei no Doko. Paper presented at the Meeting of Health of the Nation. Kosei Tokei Kyokai, Tokyo
 22. Nathan Cummings Foundation and Fetzer Institute (1997) Spiritual beliefs and the dying process: a report on a national survey. Nathan Cummings Foundation, New York, NY (conducted by The George H. Gallup International Institute, Princeton, NJ)
 23. Parle M, Maguire P, Heaven C (1997) The development of a training model to improve health professionals' skills, self-efficacy and outcome expectancies when communicating with cancer patients. *Soc Sci Med* 44:231–240
 24. Saunders C (1987) The philosophy of terminal cancer care. *Ann Acad Med Singapore* 16:151–154
 25. Townsend J, Frank AO, Fermont D, Dyer S, Karran O, Walgrove A, et al (1990) Terminal cancer care and patients' preference for place of death: a prospective study. *BMJ* 301:415–417
 26. Williams EI, Fitton F (1990) General practitioner response to elderly patients discharged from hospital. *BMJ* 300:159–161
 27. Yao CA, Chiu TY, Hu WY, Chong RB, Cheng SY, Lee LT, et al (1997) A study of initial assessment of palliative care: the viewpoints of caregivers. *Chin J Fam Med* 7:174–172