

What can family physicians contribute in palliative home care in Taiwan?

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Background. Family physicians in Taiwan have expressed low willingness to provide palliative home care.

Objective. To explore the medical needs of terminal cancer patients in home care and thus clarify the role and tasks of family physicians in providing palliative home care.

Methods. Seventy-seven terminal cancer patients discharged from a palliative care unit from July 2003 to July 2004 who had received family physician home visits were enrolled. A structured assessment form was applied to each visit.

Results. Under the collaboration by the palliative home care team and family physicians, the average interval from discharge to the first physician visit was 20.3 days and the average interval between physician visits was 37.9 days. The patients had an average of 5.9 active medical problems: the most frequent problem was pain (58.4%), followed by anorexia (42.9%) and constipation (42.9%). Forty-four patients (58.7%) died at home, while 31 patients (41.3%) eventually died in the hospital. Through multiple logistic regression analysis, patients who had never been rehospitalized [odds ratio (OR) = 12.95, 95% confidence interval (CI) = 3.41–49.19], who preferred to die at home (OR = 4.68, 95% CI = 1.21–18.09) and who were most functionally dependent with an Eastern Cooperative Oncology Group scale = 4 (OR = 4.36, 95% CI = 1.02–18.64) were found to be most likely to die at home under this care model.

Conclusion. Through palliative home care with the participation of family physicians, patients' preference could be a significant determinant of home death. Our finding can be helpful to the establishment of an ethical care model for terminal cancer patients.

Keywords. family physician, palliative care, home care, place of death.

Introduction

Cancer has been the leading cause of death in Taiwan since 1971. In 2004, >36 000 people died of cancer.¹ Although palliative care services have expanded in Taiwan over the last decade, the home death rate of cancer patients decreased from 59.9% in 1991 to 57.0% in 2004. Moreover, the rate of home care for terminal cancer patients during their last days of life is probably lower since many cancer patients are taken home from hospital only when death is imminent.^{1–3}

Although studies demonstrate that most cancer patients prefer to receive terminal care and die at home,^{4–10} worldwide the majority of cancer deaths still

occur in hospital.¹¹ A community study showed that almost half (44.6%) of the Taiwanese population chose the home as the preferred place for terminal care. Moreover, ~60% (59.4%) of those who originally chose the hospital indicated that they would change their mind and choose the home as the preferred place for terminal care if palliative home care was available.⁸ Therefore, it is important to reform palliative home care in Taiwan to meet cancer patients' needs and preferences.

Palliative home care plays an important role in fulfilling the desire of patients to be cared for and die at home. It is highly cost-effective and provides an opportunity to live and die in familiar place with close relatives.^{12–17} The old Chinese saying 'Luo Yeh Guei Gen'

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expresses the traditional belief in a good death that dying at home is as natural as the fallen leaves down to the ground. Dying at home has a special cultural meaning both for Chinese patients and their families.¹⁸ A study that analysed the barriers to the transfer of patients from the hospital to their home concluded that one effective solution is to provide palliative home care.¹⁹

Previous studies have shown that continuous care and the participation of family physicians increase the opportunity to die at home.^{20,21} As to the readiness of family physicians to provide palliative care in Taiwan, one nationwide survey revealed that ~90% of the physicians in rural areas expressed a willingness to provide palliative care. However, by big margins, they preferred to limit their services to consultation and referral (93% and 87%, respectively) and were less willing to provide home visits (40.3%). Regarding their attitudes, the top two score items in their hesitancy to provide palliative care were 'uncomfortable to take care of advanced cancer patient' and a hesitancy to 'influence normal medical activities'.²² Thus, there is a gap between patients' needs and family physicians' willingness to participate fully.

The goal of this study is to explore the medical needs and the intensity of care of palliative home care. The rate and the determinants of home death are also reviewed. This study aims to clarify the role and tasks of family physicians in providing palliative home care and thus facilitate their participation in it.

Methods

Patients

From July 2003 to July 2004, a total of 124 consecutive terminal cancer patients discharged from the palliative care unit of National Taiwan University Hospital were referred to a palliative home care programme. The home care nurse played an important role in the palliative home care team, providing follow-up phone calls, education and consultation, home visits and co-ordination of multidisciplinary services. In addition, the home care nurse arranged home visits by family physicians when necessary. Of the 124 patients, 77 patients who received home visits by family physicians were enrolled in this study. A structured assessment form was applied to each visit and the resulting data were collected and analysed.

Instruments

The assessment form was designed after the investigators scrutinized the literature in this area and consulted experts for suggestions. For ease of application and minimal disturbance to the patients, complex instruments were avoided. The assessment form was divided into two parts. The first part included demographic

data and medical records, such as sex, age, diagnosis, date of home care enrolment, date of family physician home visits, physical examinations and medical advice. The second part included the following:

1. Active medical problems including symptoms such as pain, dyspnoea, consciousness change, haemorrhage, mood disorder, anorexia, constipation, malaise, oedema, dry mouth, insomnia, nausea/vomiting, ulcerative wound, dizziness, ascites, jaundice, fever, irritable performance, mucositis and odynophagia, and also special problems or care needs. Pain and dyspnoea were assessed on a 0–10 scale. Regarding consciousness change, its duration, presentation, and the evidence as to whether it was reversible were recorded. For haemorrhage, the bleeding site and amount were documented. For mood disorder, clarification as to whether it was the result of anxiety, depression, mixed anxiety or depression or other nature was solicited.
2. Functional performance status was evaluated according to the Eastern Cooperative Oncology Group performance status scale (ECOG scale).²³ ECOG scores range from 0 (fully active) to 5 (dead), with higher scores representing more functional dependence.
3. Family function was assessed using a family adaptability, partnership, growth, affection and resolve (APGAR) index, which contained five structured questions about family interactions.²⁴ The scores were as follows: 0 = seldom, 1 = sometimes, 2 = always. A higher total score indicated higher quality of family support: 7–10 = no impairment, 4–6 = moderate impairment and 0–3 = severe impairment.
4. Socio-economic status was divided into three categories: high, median and low. Low socio-economic status was defined as those who were certified as low by the Department of Social Welfare or those who were so evaluated by social workers.
5. The degree of acceptance of poor prognosis was divided into three categories: completely accepted, partially accepted or not accepted. Patients with acute adjustment reaction or from whom the disease status was concealed were classified as 'not accepted'. Judgement as to category placement was made by the multidisciplinary home care team.
6. Dying preparation was divided into three categories: completely prepared, partially prepared or not prepared. It was documented by the multidisciplinary home care team based on the patient's and family's propriety or acceptance of death, the family's knowledge about or skills for identifying the signs or symptoms of dying and a determination as to whether the patient was peaceful or not.
7. Preference for place of death by patient or family was ascertained in the palliative care unit and re-confirmed during the home visit. If the patient was unconsciousness or had cognitive dysfunction, the information was solicited from the main caregiver.

Besides the information from the assessment form, we recorded the frequency and interval of physician visits and the occurrence of rehospitalization, where appropriate. 'Rehospitalization' excluded patients who exhibited observable signs of dying and were admitted for dying preparation according to the wishes of the patient and family.

Data collection

In this study, all family physicians providing palliative home visits took a 2-month training course in the palliative care unit that included coverage of the principles and development of palliative care, knowledge and skill for symptom control, communication skills, emotional and spiritual support, multidisciplinary approach, community resources utilization and ethical and legal issues. Those in charge of a home visit also attended the weekly meeting for home care patients. Before each visit, they routinely reviewed medical charts and discussed the case with the care team. After each visit, the physician thoroughly recorded his/her findings on the assessment form and then discussed it with a senior specialist of the palliative care unit who had responsibility for both care and record quality.

Statistical analysis

Data management and statistical analysis were performed using SPSS 11.0 statistical software. Frequency distributions were used to describe the demographic data, functional performance status, family function, socio-economic status, degree of acceptance for the poor prognosis, dying preparation, rehospitalization, place of death, frequency and interval of physician home visits and active medical problems. To define the potential determinants of home death, univariate analyses were conducted using the chi-square test and Fisher's exact method, where appropriate. Following univariate analyses, backward stepwise multiple logistic regression analysis was performed to analyse the final determinants. In the multiple logistic regression analysis, independent variables with probability values <0.25 in the univariate analyses were included. A probability value of <0.05 was considered statistically significant.

Results

Demographic data

Of 77 terminal cancer patients, 75 were followed up until their death and two were not. One dropped out of the palliative care programme because the family withdrew the do-not-resuscitate order, while the other was referred to a hospital closer to home. Their records of rehospitalization or place of death were omitted and not included in the analysis.

The characteristics of the 77 patients are summarized in Table 1. There were 35 male patients (45.5%)

TABLE 1 Characteristics of patients (N = 77)

Variable	n	%
Sex		
Men	35	45.5
Women	42	54.5
Age (years) (range: 5–92, mean: 69.3)		
<65	24	31.2
≥65	53	68.8
Primary site of tumour		
Lung	17	22.1
Colon and rectum	12	15.6
Head and neck	9	11.7
Liver	7	9.1
Breast	5	6.5
Stomach	4	5.2
Kidney	3	3.9
Pancreas	3	3.9
Other	17	22.1
ECOG		
0–1	0	0
2	8	10.4
3	44	57.1
4	25	32.5
Family function (APGAR score)		
1–3	0	0
4–6	3	3.9
7–10	64	83.1
Not mentioned	10	10
Socio-economic status		
Low	1	1.3
Median	73	94.8
High	3	3.9
Degree of acceptance for the poor prognosis		
Not accepted	1	1.3
Partially accepted	35	45.5
Completely accepted	37	48.1
Not mentioned	4	5.2
Dying preparation		
Not prepared	4	5.2
Partially prepared	38	49.4
Completely prepared	34	44.2
Not mentioned	1	1.3
Rehospitalization (excluded two who dropped out)		
No	34	45.3
Yes	41	54.7
Place of death (excluded two who dropped out)		
Home	44	58.7
Hospital	31	41.3

and 42 female patients (54.5%), with a mean age of 69.3 years and range from 5 to 92 years. A total of 53 patients (68.8%) were >65 . The primary sites of cancer were the lung (22.1%), colon–rectum (15.6%) and head–neck (11.7%). The functional performance status of the patients was highly dependent with the proportion of those with a functional status rated as 3 and 4 on the ECOG scale 57.1% and 32.5%, respectively. The family function of most patients was almost without impairment (83.1%). Socio-economic status was overwhelmingly in the median level (94.8%). As to the degree of acceptance for the poor prognosis, the proportions rated as completely accepted, partially accepted and not accepted were 48.1%, 45.5% and

1.3%, respectively. With regard to dying preparation, the proportions rated as completely prepared, partially prepared and not prepared were 44.2%, 49.4% and 5.2%, respectively. Among the 75 patients followed until their death, 41 (54.7%) were rehospitalized. Forty-four patients (58.7%) died at home, while 31 patients (41.3%) died in the hospital.

The frequency and interval of family physician home visit

The frequency and interval of family physician home visit are demonstrated in Table 2. The duration of enrolment in the palliative home care programme was 54.2 days on average, ranging from 1 to 241 days. Total home visits by family physicians averaged 1.8, ranging from 1 to 6. Under the holistic care by the palliative home care team, the average interval from discharge to the first time of family physician visit was 20.3 days and the average interval between visits was 37.9 days. Those who needed frequent family physician visits (with an interval of <1 week) accounted for only 7.8%.

Active medical problems

According to the initial assessment by family physicians during the first home visits, the patients suffered on average 5.9 active problems with a range from 1 to 11 (Table 3). The most frequent problem was pain (58.4%), followed by anorexia (42.9%), constipation (42.9%), mood disorder (36.4%) and malaise (35.1%). Among all symptoms, we found that dyspnoea, consciousness change and haemorrhage were relatively more disturbing. We analysed the correlation between each symptom and total visits and average interval of visits, but there was no statistically significant finding.

Determinants of home death

To define the potential determinants of home death, univariate analyses were conducted (Table 4). The independent variables with *P* values <0.25 in univariate analyses were entered into backward stepwise multiple logistic regression analysis, inclusive of rehospitalization, patient's preference for place of death, ECOG score, the degree of acceptance for the poor prognosis, family's preference for place of death, pain and colorectal cancer. In the multiple logistic regression analysis (Table 5), rehospitalization (no), patient's preference for place of death (home) and ECOG (scale = 4) were independently correlated with home death [odds ratio (OR) = 12.95, 95% confidence interval (CI) = 3.41–49.19; OR = 4.68, 95% CI = 1.21–18.09; OR = 4.36, 95% CI = 1.02–18.64, respectively]. In other words, home care patients who were never rehospitalized, who preferred to die at home and who were at the greatest functionally dependent status were most likely to die at home. This model accounted for 47.8% of the variance.

TABLE 2 *The frequency and interval of family physician home visit (N = 77)*

Variable	<i>n</i>	%
Duration of palliative home care (days)	(range 1–241, mean: 54.2)	
1–7	4	5.2
8–30	28	36.4
31–90	33	42.9
>90	12	15.6
Total physician visits (times)	(range: 1–6, mean: 1.8)	
1	47	61.0
2	15	19.5
3	6	7.8
4	6	7.8
5	2	2.6
6	1	1.3
Interval between each physician visit (days)	(range: 1–201, mean: 37.9)	
1–7	6	7.8
8–30	45	58.4
31–90	19	24.7
>90	7	9.1

Average interval from discharge to the first time of physician visit: 20.3 days.

TABLE 3 *Active medical problems of terminal cancer patients^a (N = 77)*

Variable	<i>n</i>	%
Pain	45	58.4
Anorexia	33	42.9
Constipation	33	42.9
Mood disorder	28	36.4
Malaise	27	35.1
Oedema	23	29.9
Consciousness change	20	26.0
Dyspnoea	17	22.1
Dry mouth	16	20.8
Insomnia	14	18.2
Haemorrhage	13	16.9
Nausea or vomiting	12	15.6
Ulcerative wound	9	11.7
Dizziness	9	11.7
Ascites	8	10.4
Total number of active medical problems	(range: 1–11, average: 5.9)	
1–3	8	10.4
4–6	44	57.1
7–9	17	22.1
≥10	8	10.4

^aOnly those >10% were listed in this table.

Discussion

Summary of main findings

In our study like previous ones,²⁵ pain is the most common active medical problem. Thus, competency in pain control is essential for family physicians. Notably, mood disorder was not secondary to other physical symptoms and accounted for 36.4%. Moreover,

TABLE 4 Univariate analysis for determinants of home death (N = 75)

Variable	Home death n (%)	Hospital death n (%)	OR	P value
Sex			1.11	0.826
Men	21 (28)	14 (19)		
Women	23 (31)	17 (23)		
Age			1.31	0.587
≥65	31 (41)	20 (27)		
<65	13 (17)	11 (15)		
ECOG			3.95	0.013
ECOG = 4	19 (25)	5 (7)		
ECOG < 4	25 (33)	26 (35)		
Duration of palliative home care			1.52	0.388
≤30 days	20 (27)	11 (15)		
>30 days	24 (32)	20 (27)		
Total physician visits			1.15	0.774
1	27 (36)	18 (24)		
>1	17 (23)	13 (17)		
Rehospitalization			14.46	<0.001
No	30 (40)	4 (5)		
Yes	14 (19)	27 (36)		
Degree of acceptance for poor prognosis			1.73	0.246
Completely	23 (31)	12 (16)		
Others	21 (28)	19 (25)		
Dying preparation			1.45	0.439
Completely	21 (28)	12 (16)		
Others	23 (31)	19 (25)		
Patient's preference of place of death			4.56	0.004
Home	23 (31)	6 (9)		
Hospital	21 (28)	25 (33)		
Family's preference of place of death			2.61	0.065
Home	19 (25)	7 (9)		
Hospital	25 (33)	24 (32)		
Pain			1.81	0.213
Yes	29 (39)	16 (21)		
No	15 (20)	15 (20)		
Dyspnoea			1.01	0.988
Yes	10 (13)	7 (9)		
No	34 (45)	24 (32)		
Haemorrhage			1.74	0.539
Yes	9 (12)	4 (5)		
No	35 (47)	27 (36)		
Consciousness change			0.96	0.937
Yes	11 (15)	8 (11)		
No	33 (44)	23 (31)		
Lung cancer			1.01	0.988
Yes	10 (13)	7 (9)		
No	34 (45)	24 (32)		
Colorectal cancer			0.44	0.192
Yes	5 (7)	7 (9)		
No	39 (52)	24 (32)		
Head and neck cancer			1.47	0.728
Yes	6 (8)	3 (4)		
No	38 (51)	28 (37)		

TABLE 5 Multiple regression analysis for determinants of home death

Variable	β	Wald	χ ²	P value	OR (95% CI)
Rehospitalization (no)	2.561	14.147	<0.001		12.95 (3.41–49.19)
Patient's preference of place of death (home)	1.543	5.001	0.025		4.68 (1.21–18.09)
ECOG = 4	1.473	3.953	0.047		4.36 (1.02–18.64)
Intercept	-1.486	8.917	0.020		

be cared for at home with high quality care and education provided during hospitalization, follow-up and help from home care nurses and timely assessments and advice by family physicians.

To ensure the care quality, we conducted a 'good-death scale' and an 'audit scale for good-death service' for our patients. Both scales were integrated into the routine practice in the palliative care unit of National Taiwan University Hospital.^{26,27} The good-death scale was based on Weisman's definition of a good death and the opinions of experienced professionals in palliative care.^{28,29} It consisted of five items: awareness, acceptance, propriety, timeliness and comfort. The audit scale for good-death service was designed to evaluate the performance of palliative care service and was classified into six categories including physical care, autonomy, emotional support, communication, continuity of life and closure. The patients in our study had similar results for both scales to those who were simply visited by the home care nurse or who died in the palliative care unit, and even better outcome in several aspects.

Strengths and limitations of the study

To our knowledge, this study is one of the first to investigate the role of family physicians in palliative home care from the actual experiences of medical care, especially in the Asia-Pacific region. Owing to the challenge and complexity of palliative home care, it was a difficult task to integrate the assessment into daily practice. Compared with studies conducted in hospital or from registered data, this study offers some practical and valuable information.

There are, however, certain limitations to this study. Firstly, all patients had been discharged from the palliative care unit of a single university hospital and received family physician home visits at the direction of the home care nurse. Secondly, the analysis of each initial assessment could not fully capture the dynamic progression of the disease. Thirdly, not all potential determinants of place of death were evaluated in this study, and most of the instruments in our assessment form were simple, not complicated validated, instruments. However, considering the complexity of home care practice and the functional or cognitive status of the patients, it was deemed more ethical to minimize the disturbance to the patients and to keep each home visit as non-evasive as possible.

insomnia (18.2%) and irritable behaviour (5.2%) possibly were related to mood problems. This finding reiterates the importance of a multidisciplinary approach in palliative home care.

The frequency of family physician home visits in our study was not as high as expected. This study demonstrates that terminal cancer patients can appropriately

Comparison with existing literature

One of the most important findings of this study concerns the determinants of home death of terminal cancer patients. Previous studies have focused on social characteristics, support networks, functional status and care needs of patients or on health system factors.¹¹ However, patients' preference has rarely been taken into account. Although patients' preference could be associated with the factors mentioned above, it is undoubtedly the focus of palliative care and should not be ignored when conducting similar research.

With regards to rehospitalization, our finding was consistent with the conclusions of other studies.^{18,30,31} Rehospitalization might be related to difficulty in symptom management and to the need for more intensive care and intervention, thus resulting in a breakdown of home death. As to functional status, contrary to western countries, our finding was consistent with previous reports from Asian countries.^{30,31} This may be the result of cultural differences in the patient's awareness and acceptance of impending death. Asian patients with cancer may be more likely to recognize that their disease is far advanced when their physical condition deteriorates, and those who are fully aware of their prognosis and imminence of death may be likely to choose home care and death at home. In contrast, patients who still retain some degree of functional independence might not see themselves as terminally ill and might grasp every opportunity to fight their disease, thus increasing the choice of rehospitalization and hospital death.³¹

Another important finding is that family's preference for place of death was not the determinant of selecting home death under this care programme. In practice, the transfer of patients from hospital to their home for a palliative home care programme is difficult, and some obstacles do come from their family.³² In Asian countries, the family's preference sometimes overrides the patient's preference.^{20,33,34} In such family-oriented circumstances, it is also common that the patient's family tends to conceal the truth about the disease status, thus limiting the patient's participation in making the decision.³⁵ In this study, the patient's preference tended to override the family's preference in considering the place of death. Although the reason was not clear, it could be because the care programme removed the barriers to home care and emphasized the goal of patient-centred care.

Implications for future research or clinical practice

Palliative home care plays an important role in fulfilling the desire of terminal cancer patients to be cared for and die at home. Family physicians undoubtedly play an important role in palliative home care. Our study clarified the role of family physicians in palliative home care and found that the frequency of physician home visits was not as high as anticipated.

Timely assessments and advice by family physicians not only contribute towards good quality care but also facilitate the preferences of patients, thus becoming a significant force for home death even where the family situation is difficult. Our finding can be helpful in the establishment of an ethical care model for terminal cancer patients, especially in the countries where family physicians are moving towards increased participation in palliative home care.

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Declaration

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Conflict of interest: none.

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