



Effectiveness of palliative care consultation service on caregiver burden over time between terminally ill cancer and non-cancer family caregivers

Li-Fen Wu^{1,2,3} · Chin Lin⁴ · Yu-Chun Hung^{1,2} · Li-Fang Chang^{1,2,3} · Ching-Liang Ho⁵ · Hsueh-Hsing Pan^{1,2}

Received: 29 May 2019 / Accepted: 1 April 2020 / Published online: 15 April 2020
© Springer-Verlag GmbH Germany, part of Springer Nature 2020

Abstract

Purpose The responsibility of taking care of terminal patients is accepted as a role of family members in Taiwan. Only a few studies have focused on the effect of palliative care consultation service (PCCS) on caregiver burden between terminal cancer family caregivers (CFCs) and non-cancer family caregivers (NCFCs). Therefore, the purpose of this study is to address the effect of PCCS on caregiver burden between CFC and NCFC over time.

Methods A prospective longitudinal study was conducted in a medical center in northern Taiwan from July to November 2017. The participants were both terminally ill cancer and non-cancer patients who were prepared to receive PCCS, as well as their family caregivers. Characteristics including family caregivers and terminal patients and Family Caregiver Burden Scale (FCBS) were recorded pre-, 7, and 14 days following PCCS. A generalized estimating equation model was used to analyze the change in the level of family caregiver burden (FCB) between CFC and NCFC.

Results The study revealed that there were no statistically significant differences in FCB between CFC and NCFC 7 days and 14 days after PCCS ($p > 0.05$). However, FCB significantly decreased in both CFC and NCFC from pre-PCCS to 14 days after PCCS ($\beta = -12.67$, $p = 0.013$). PPI of patients was the key predictor of FCB over time following PCCS ($\beta = 1.14$, $p = 0.013$).

Conclusions This study showed that PCCS can improve FCB in not only CFC but also NCFC. We suggest that PCCS should be used more widely in supporting family caregivers of terminally ill patients to reduce caregiver burden.

Keywords Palliative care consultation service · Caregiver burden · Terminally ill patient · Cancer patient · Non-cancer patient

Background

According to statistics, 170,000 deaths occurred in Taiwan in 2017, of which nearly 50,000 were caused by cancer [1].

✉ Hsueh-Hsing Pan
pshing2001@gmail.com

¹ Department of Nursing, Tri-Service General Hospital, Taipei City, Taiwan

² School of Nursing, National Defense Medical Center, Taipei City, Taiwan

³ Graduate Institute of Medical Sciences, National Defense Medical Center, Taipei, Taiwan

⁴ School of Public Health, National Defense Medical Center, Taipei City, Taiwan

⁵ Division of Hematology and Oncology, Department of Internal Medicine, Tri-Service General Hospital, National Defense Medical Center, Taipei City, Taiwan

Taiwanese are influenced profoundly by Confucian family values, and the family institution is rooted deeply in Taiwanese society. In the process of caring for terminally ill patients, family caregivers play an important role; however, their responsibilities and obligations are usually taken for granted [2]. During disease progression, primary family caregivers often worry about a patient's condition; experience sadness as a patient nears death; face many issues, such as the choice of care facilities, opinions of family members, and care-related manpower; and suffer personal health problems, such as anxiety, depression, sleep disturbance, and physical exhaustion. Moreover, with the responsibility of long-term care, caregivers may be forced to change their lifestyles and abandon social activities in which they had previously engaged. When caregivers experience physical, psychological, social, and economic difficulties, they may be susceptible to caregiver burden [3–6].

To maintain the best quality of survival and life for patients and their families, Taiwan has promoted hospice palliative

care (HPC) services since 1996. In 2000, HPC was included in the list of services reimbursed by the National Health Insurance (NHI) program of Taiwan. The services provided during the initial years include home hospice care and hospice care in hospitals for cancer patients. In 2005, palliative care consultation service (PCCS) was promoted and included in the list of services reimbursed by the NHI program, so that more terminally ill patients could receive HPC services. In 2009, patients diagnosed with eight terminal non-cancer diseases were provided with HPC under the NHI program: organic mental disorders in old age, severe neurological diseases, heart failure, chronic obstructive pulmonary disease, terminal pulmonary disease, chronic liver disease or liver cirrhosis, acute renal failure, and chronic renal failure. According to statistics, the use of HPC by cancer patients during the last year of life shows a substantial increase from 7% in 2000 to 58.7% in 2016. However, only 9% of patients whose deaths were caused by the eight types of non-cancer diseases used HPC services before their death [1, 7].

In recent years, PCCS has become among the major services offered by hospitals. One of the distinctive features of PCCS is that it is provided by a multidisciplinary team comprising professionals with different capabilities, including doctors, nurses, psychologists, social workers, pharmacists, and chaplains. Through consultations, the original medical and HPC teams jointly provide a HPC treatment program and HPC to terminally ill patients and their families in non-hospice wards [8–10]. The HPC team performs holistic assessment of a patient's condition and symptoms, as well as the expectations of the patient and his/her family; provides advice on symptomatic care to the patient, his/her family members, and the original medical team; utilizes effective communication skills for the discussion of follow-up care plans with the patient and his/her family; assists in medical decision-making processes; and provides direct physical, psychological, social, and spiritual care to the patient and his/her family as needed [11]. Many studies have shown that PCCS can enhance the understanding of diseases in patients and their families and alleviate symptoms of terminally ill patients. Through joint discussions on the issues faced by terminally ill patients, PCCS can also help patients and their families understand the disease prognosis and treatment goals, fulfill the needs of patients and their families, and assist patients and their families during the former's last stage of life [8, 10, 12, 13]. The outcomes of PCCS were related to patients' gender, age, disease diagnosis, performance status, timing of do-not-resuscitate (DNR) signature, and spiritual problems [14].

Studies have indicated that the caregiving skills of primary family caregivers of terminally ill patients are enhanced effectively through HPC. With the physical, psychological, social, and spiritual support provided by HPC teams, the primary caregivers can get adequate rest, which is helpful toward the maintenance of better caregiving capabilities and positive

emotions and the reduction of caregiver burden [15]. Taiwanese studies have indicated that PCCS can alleviate effectively the caregiver burden of primary family caregivers of terminal cancer patients [4]. However, only a few studies have examined the effect of PCCS on caregiver burden using a prospective longitudinal methodology, wherein follow-ups are conducted with the subjects. In addition, a lack of research has compared the differences between the influences of PCCS intervention on caregiver burden of terminal cancer family caregiver (CFC) and non-cancer family caregiver (NCFC). Therefore, the present study aimed to perform an investigation of the variation in trends in caregiver burden of terminal CFC and NCFC with PCCS, to determine the differences in caregiver burden between the two groups of caregivers with PCCS.

Methods

Study design and population

The present study employed a prospective longitudinal methodology. Two groups, namely terminally ill cancer and non-cancer patients who were prepared to receive PCCS, together with their family caregivers, were recruited from a medical center in northern Taiwan between July and November 2017. The following inclusion criteria were applied: aged over 20 years, ability to communicate in Mandarin or Taiwanese, awareness of the study, and willingness to participate in the study. In addition, the terminally ill cancer and non-cancer patients included were those whose prognosis was considered to be less than 6 months and whose consciousness was intact. The family caregivers included were those who were mainly responsible for taking care of such patients. Participants were provided with information on study protocol. After written informed consent was obtained from each of the participants, the researcher collected data via questionnaires before PCCS and 7 and 14 days following the PCCS. Data collection concluded when the patient no longer received PCCS, such as when the patient was transferred to a hospice ward, received hospice home care, was discharged, or became deceased. The study was conducted after receiving approval from the Institutional Review Board (2-106-05-071).

PCCS

The process flow of PCCS at the medical center is as follows:

1. When a terminally ill patient in an acute care ward requires HPC, the primary physician will consult a palliative care specialist. The palliative care specialist and a hospice nurse will conduct the first visit and explain the concept of HPC to the patient and his or her family

members. After confirming their willingness and receiving informed consents, they begin to receive PCCS.

2. PCCS is provided by a multidisciplinary team, often comprising palliative care specialists, hospice nurses, social workers, and a chaplain. The objective of PCCS is to assess the physical, psychological, social, and spiritual conditions of the patient and his or her family, and provide recommendations regarding symptom control and psychosocial and family support.
3. The PCCS team will visit the patient once or twice a week. During each visit, the team will assess the condition of the patient and his or her family members. Their individual findings are then reported and discussed during the weekly HPC team meeting.
4. During the weekly meeting, the PCCS team will likewise help the patient and his or her family with advance care planning, which consists of making plans regarding the patient's future health care. This may include an evaluation of the possibilities of transferring to a hospice ward, dispensing with hospice home care, or staying in the initial primary care facility.
5. PCCS is terminated when the issues of the patients and his or her family members, such as pain control and psychosocial problems, are resolved, or when the patient is transferred to a hospice ward or hospice home care, is discharged, or has deceased.

Measurements

Characteristics of family caregiver and terminal patient

The data collected include family caregiver's age, gender, educational level, religious belief, marital status (single or married), relationship with the patient (spouse or non-spouse), living arrangement (living together with the patient or not), closeness level with patient (Likert scale 1–5, 1 = no closeness at all and 5 = very close), and perceived disease severity of the patient (Likert scale 1–5, 1 = not serious at all and 5 = very serious).

Patients' data included age, gender, educational level, religious belief, marital status, caregiver identity (spouse or non-spouse), economic source (self or others), economic status, comorbidity (yes or no), perceived disease severity (Likert scale 1–5, 1 = not serious at all and 5 = very serious), DNR signature pre-PCCS or post-PCCS, symptom distress, and palliative prognostic index (PPI).

The Symptom Distress Scale (SDS) was originally developed by McCorkle and Young [16] and modified into Chinese Modified Form (SDS-CMF) by Lai (1998) [17]. SDS-CMF was used to measure the symptom distress in the past week and consisted of 25 items of common symptoms; items were rated on a five-point Likert Scale, where 1 represents "no distress" and 5 "severe distress." The total scores of symptom

distress ranged from 25 to 125, with a higher score indicating more severe in symptom distress level. The Cronbach's α was 0.92 in Lai's study [17]. In this present study, Cronbach's α was 0.950, 0.937, and 0.968 for 68 terminal, 46 terminal cancer, and 22 terminal non-cancer patients, respectively.

Morita et al. (1999) developed PPI for the survival prediction of terminally ill cancer patients [18]. PPI was defined by performance status, oral intake, edema, dyspnea at rest, and delirium. The total scores of PPI ranged from 0 to 15, with a lower score indicating longer survival time. When PPI is more than 6, the survival time was predicted to be less than 3 weeks, with a sensitivity of 80% and a specificity of 85%. When PPI is more than 4, the survival time was predicted to be less than 6 weeks, with a sensitivity of 80% and a specificity of 77% [18].

Family Caregiver Burden Scale

Family Caregiver Burden Scale (FCBS) was developed by Hong and Lin (2010) to assess caregivers' burden of caring for terminal cancer patients [19]. FCBS consisted of 17 items and was divided into four subscales, including physical-psychological (7 items), spiritual (4 items), economic (3 items), and daily-living (3 items) burden. It was rated on a five-point Likert scale, where 1 represents "never" and 5 "always." The total scores of FCBS ranged from 17 to 85, with a higher score indicating a higher burden level. The content validity was 0.98. Cronbach's α was 0.89 for 100 terminal CFC in Hong and Lin's study [19]. In the present study, Cronbach's α was 0.972, 0.979, and 0.957 for 68 family caregivers, 46 CFC, and 22 NCFC, respectively. In addition, the Cronbach's α range was 0.934–0.966 in the subscales.

Statistical analysis

Data were analyzed using IBM SPSS software (SPSS 20.0 for windows). Descriptive statistics, such as frequency and percentage, were used to describe category variables. The mean and standard deviation (SD) were used to describe continuous variables. The baseline heterogeneity between CFC and NCFC was analyzed by *t* test and chi-squared test. Fisher exact test was also used to adjust the cell less than 5. Repeated measurement using the generalized estimating equation (GEE) was appropriate, since the latter is equipped to handle missing data and does not require that the outcome be normally distributed [20]. Therefore, GEE was used to determine the FCBS or overall caregiver burden, using the subscales of physical-psychological, spiritual, daily-living, and economic burden before PCCS, and 7 days and 14 days following PCCS. After testing each variable in GEE model, family caregiver burden (FCB) of CFC and NCFC pre-PCCS was analyzed, and the significant variables were adjusted in the 7 days and 14 days following PCCS. The FCB of family caregiver of terminal patient pre-PCCS was also analyzed, and

the significant variables were adjusted in the 7 days and 14 days following PCCS. A p value of <0.05 was considered statistically significant.

Results

Data were collected from 46 CFC and 22 NCFC before PCCS, 27 CFC and 13 NCFC 7 days following PCCS, and 8 CFC and 3 NCFC 14 days following PCCS. The flowcharts of CFC and NCFC are shown in Fig. 1. Baseline characteristics of participants of CFC and NCFC and terminal patients are shown in Table 1. The two groups of family caregivers exhibited no significant differences in baseline characteristics, except for the patients' age ($p < 0.001$), patients' caregiver ($p = 0.028$), and PPI ($p = 0.017$).

There were no statistically significant differences in the mean values of FCB, including physical-psychological, spiritual, daily-living, and economic burden before PCCS and 7 and 14 days following PCCS between the CFC and NCFC ($p > 0.05$). The details are shown in Table 2.

We used the GEE model of FCB to test each variable of baseline characteristics of family caregivers and terminal patients pre-PCCS and 7 and 14 days following PCCS. The data showed that patients' religious belief was statistically significant with physical-psychological burden ($\beta = 4.31$, $p = 0.005$); their economic sources with spiritual burden ($\beta = 2.45$, $p = 0.017$); and their PPI with FCB ($\beta = 1.14$, $p =$

0.018), including physical-psychological ($\beta = 0.46$, $p = 0.020$), spiritual ($\beta = 0.31$, $p = 0.008$), and daily-living ($\beta = 0.23$, $p = 0.024$) burden pre-PCCS and 7 and 14 days following PCCS. The details are shown in Table 3.

After adjusting for patient's religious belief, economic sources, and PPI, the changes in FCB toward PCCS between CFC and NCFC assessed at different time points are presented in Table 4. In comparing the FCB of CFC and NCFC, including physical-psychological, spiritual, daily-living, and economic burden, no significant change in scores was found in from before to 7 days and 14 days following PCCS ($p > 0.05$). Patients' PPI was the key predictor of FCB as well as physical-psychological, spiritual, daily-living, and economic burden over time following PCCS. In addition, compared with patients with religious belief, those with no religious belief had significantly increased physical-psychological burden over time following PCCS ($\beta = 3.79$, $p = 0.020$). Compared with patients whose economic sources were from others, those whose economic sources were from themselves had significantly increased spiritual burden over time following PCCS ($\beta = 2.66$, $p = 0.005$).

The GEE model of FCB in family caregivers of terminal patients pre-PCCS and 7 and 14 days following PCCS is shown in Table 5. In terms of FCB of terminal patients, there was a significant decrease from before PCCS to 14 days following PCCS ($\beta = -12.67$, $p = 0.013$). In addition, physical-psychological ($\beta = -5.62$, $p = 0.022$), daily-living burden ($\beta = -2.45$, $p = 0.043$), and economic ($\beta = -2.15$, $p = 0.019$)

Fig. 1 The flowcharts of study. PCCS palliative care consultation service

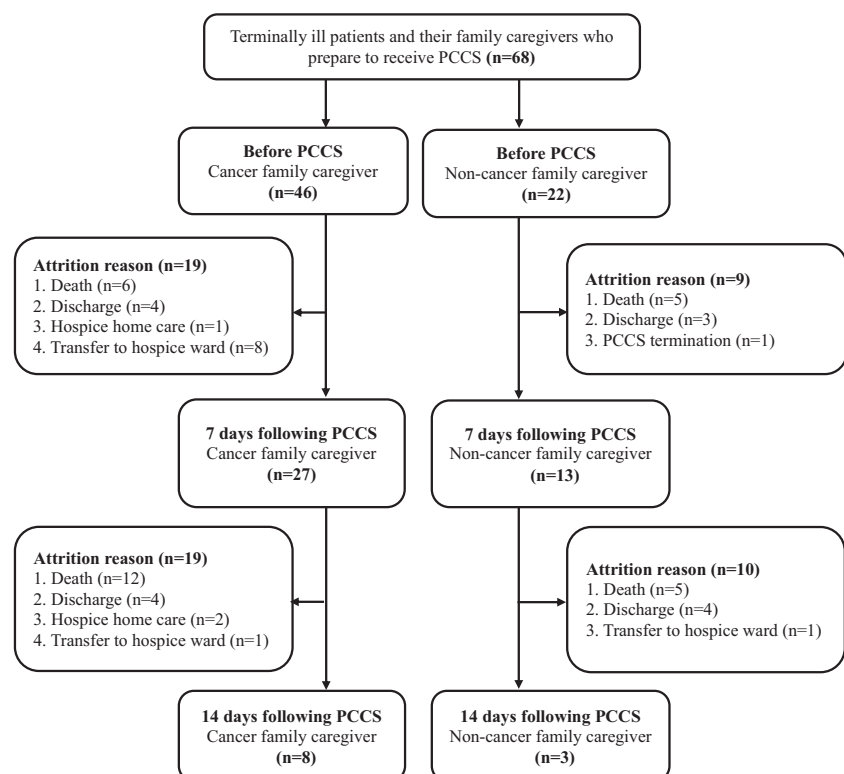


Table 1 Characteristics of terminal cancer and non-cancer family caregivers and patients

Variables	Cancer (<i>n</i> = 46)	Non-cancer ^b (<i>n</i> = 22)	<i>p</i> value
Family caregiver			
Age (mean ± SD)	52.6 ± 10.5	56.4 ± 11.8	0.180
Range	24.2–76.5	33.5–81.0	
Gender			0.266
Male	12 (26.1)	9 (40.9)	
Female	34 (73.9)	13 (59.1)	
Educational level			0.301
High school below	24 (52.2)	8 (36.4)	
Specialist or above	22 (47.8)	14 (63.6)	
Religious belief			0.086 ^a
Yes	29 (63.0)	19 (86.4)	
No	17 (37.0)	3 (13.6)	
Marital status			0.551
Single	10 (21.7)	7 (31.8)	
Married	36 (78.3)	15 (68.2)	
Relationship with patient			0.255 ^a
Spouse	16 (34.8)	4 (18.2)	
Non-spouse	30 (65.2)	18 (81.8)	
Living together			0.430
Yes	29 (63.0)	11 (50.0)	
No	17 (37.0)	11 (50.0)	
Closeness level with patient (mean ± SD)	4.6 ± 0.5	4.6 ± 0.7	0.639
Perceived disease severity of patient (mean ± SD)	4.0 ± 0.8	4.4 ± 0.8	0.803
Patient			
Age (mean ± SD)	67.6 ± 15.3	83.6 ± 11.0	< 0.001
Range	21.6–94.3	61.9–99.6	
Gender			0.795
Male	26 (56.5)	11 (50.0)	
Female	20 (43.5)	11 (50.0)	
Educational level			0.707 ^a
High school below	39 (84.8)	20 (90.9)	
Specialist or above	7 (15.2)	2 (9.1)	
Religious belief			0.523 ^a
No	11 (23.9)	3 (13.6)	
Yes	35 (76.1)	19 (86.4)	
Marital status			0.230
Single	16 (34.8)	11 (50.0)	
Married	30 (65.2)	11 (50.0)	
Caregiver identity			0.028 ^a
Spouse	19 (41.3)	3 (13.6)	
Non-spouse	27 (58.7)	19 (86.4)	
Economic sources			0.260 ^a
Self	15 (32.6)	4 (18.2)	
Others	31 (67.4)	18 (81.8)	
Economic status			1.000
≤ 20,000 NT dollars	30 (65.2)	14 (63.6)	
> 20,000 NT dollars	16 (34.8)	8 (36.4)	
Comorbidity			1.000 ^a
Yes	41 (89.1)	20 (90.9)	

Table 1 (continued)

Variables	Cancer (<i>n</i> = 46)	Non-cancer ^b (<i>n</i> = 22)	<i>p</i> value
No	5 (10.9)	2 (9.1)	
Perceived disease severity (mean ± SD)	4.0 ± 0.8	3.7 ± 1.5	0.352
DNR signature			0.274 ^a
Pre-PCCS	28 (60.9)	17 (77.3)	
Post-PCCS	18 (39.1)	5 (22.7)	
Symptom distress (mean ± SD)	61.6 ± 20.3	54.9 ± 28.3	0.264
PPI (mean ± SD)	6.1 ± 4.1	8.8 ± 4.5	0.017

SD standard deviation, *PCCS* palliative care consultation service, *PPI* palliative prognostic index

^a Fisher exact test

^b Of the non-cancer patients, 9 had terminal pulmonary disease, 4 had heart failure, 3 had organic mental disorders in old age, 3 had chronic obstructive pulmonary disease, 2 had chronic liver disease or liver cirrhosis, and 1 had acute renal failure

burden of family caregivers of terminal patients decreased significantly 14 days following PCCS compared with pre-PCCS.

Discussion

This study suggested that FCB of CFC and NCFC was significantly reduced 14 days following PCCS. A similar study in Taiwan indicated that PCCS assisted health care teams in reducing caregiver burden for families of terminal cancer

patients, especially 2 and 12 days following PCCS [4]. Another observational cohort study in Germany indicated that cancer caregiver burden did not change over time until the death of the patient [21]. However, these two studies used different instruments to measure caregiver burden and did not include non-cancer patients or caregivers from their families. In addition, the latter focused on home-based palliative care instead of hospital-based care. Consequently, based on the results of these studies, it was difficult to understand the changes in FCB in the non-cancer population.

Table 2 Family caregiver burden between family caregivers of terminal cancer and non-cancer patients pre-PCCS and 7 and 14 days following PCCS

Variables	CFC (mean ± SD)	NCFC (mean ± SD)	<i>p</i> value
Pre-PCCS	<i>N</i> = 46	<i>N</i> = 22	
Family caregiver burden	46.1 ± 21.5	46.7 ± 20.1	0.911
Physical-psychological burden	18.2 ± 8.9	19.4 ± 9.7	0.612
Spiritual burden	10.4 ± 5.1	11.1 ± 5.6	0.646
Daily-living burden	8.7 ± 4.6	8.7 ± 4.3	0.993
Economic burden	8.8 ± 4.5	7.6 ± 4.5	0.297
7 days following PCCS	<i>N</i> = 27	<i>N</i> = 13	
Family caregiver burden	42.0 ± 21.9	44.5 ± 19.6	0.728
Physical-psychological burden	16.6 ± 9.2	18.2 ± 8.5	0.618
Spiritual burden	9.8 ± 5.8	10.6 ± 5.6	0.667
Daily-living burden	7.6 ± 4.8	8.4 ± 3.8	0.586
Economic burden	8.1 ± 4.6	7.4 ± 3.7	0.643
14 days following PCCS	<i>N</i> = 8	<i>N</i> = 3	
Family caregiver burden	33.9 ± 20.0	36.7 ± 20.1	0.841
Physical-psychological burden	12.9 ± 8.2	15.0 ± 7.5	0.706
Spiritual burden	8.4 ± 5.2	9.3 ± 6.1	0.800
Daily-living burden	6.5 ± 4.5	6.3 ± 3.5	0.956
Economic burden	6.1 ± 5.0	6.0 ± 3.0	0.969

PCCS palliative care consultation service, *CFC* cancer family caregiver, *NCFC* non-cancer family caregiver, *SD* standard deviation

Table 3 Univariate GEE model of family caregiver burden in family caregiver pre-, 7 days, and 14 days following PCCS

Variable	Family caregiver burden		Physical-psychological burden		Spiritual burden		Daily-living burden		Economic burden	
	β	<i>p</i> value	β	<i>p</i> value	β	<i>p</i> value	β	<i>p</i> value	β	<i>p</i> value
Family caregiver										
Terminal patient										
Cancer	-0.73	0.872	-1.29	0.500	-0.72	0.511	-0.08	0.936	1.27	0.208
Non-cancer	Reference		Reference		Reference		Reference		Reference	
Age	-0.11	0.561	-0.01	0.940	-0.01	0.871	-0.01	0.790	-0.07	0.065
Gender										
Male	0.17	0.970	0.35	0.856	0.35	0.721	0.20	0.849	0.88	0.380
Female	Reference		Reference		Reference		Reference		Reference	
Educational level										
High school below	-0.29	0.945	0.16	0.925	-0.53	0.603	-0.30	0.740	0.15	0.880
Specialist or above	Reference		Reference		Reference		Reference		Reference	
Religious belief										
Yes	1.01	0.799	0.52	0.733	0.19	0.855	0.12	0.898	0.13	0.895
No	Reference		Reference		Reference		Reference		Reference	
Marital status										
Single	4.67	0.252	2.29	0.167	0.80	0.478	0.56	0.517	0.81	0.391
Married	Reference		Reference		Reference		Reference		Reference	
Relationship with patient										
Non-spouse	3.49	0.470	1.27	0.519	0.41	0.705	0.48	0.665	1.53	0.162
Spouse	Reference		Reference		Reference		Reference		Reference	
Living together										
Yes	1.03	0.815	0.37	0.839	-0.09	0.934	0.40	0.665	0.19	0.857
No	Reference		Reference		Reference		Reference		Reference	
Closeness level with patient	0.34	0.931	0.51	0.763	-0.76	0.451	0.09	0.923	0.71	0.318
Perceived disease severity of patient	1.74	0.539	0.86	0.452	0.47	0.517	0.26	0.669	0.36	0.557
Patient										
Age	-0.008	0.914	0.02	0.567	0.01	0.676	-0.002	0.872	-0.02	0.127
Gender										
Male	-3.75	0.375	-1.86	0.277	-0.29	0.776	-0.39	0.675	-1.32	0.172
Female	Reference		Reference		Reference		Reference		Reference	
Educational level										
High school below	-2.21	0.679	-0.26	0.909	-0.08	0.937	-1.02	0.385	-0.86	0.561
Specialist or above	Reference		Reference		Reference		Reference		Reference	
Religious belief										
No	5.85	0.189	4.31	0.005	0.52	0.653	0.33	0.376	0.66	0.561
Yes	Reference		Reference		Reference		Reference		Reference	
Marital status										
Single	-0.49	0.911	0.53	0.764	-0.73	0.485	-0.20	0.829	-0.10	0.922
Married	Reference		Reference		Reference		Reference		Reference	
Caregiver										
Non-spouse	2.80	0.546	1.43	0.452	0.05	0.961	0.08	0.937	1.37	0.175
Spouse	Reference		Reference		Reference		Reference		Reference	
Economic sources										
Self	6.05	0.175	2.08	0.250	2.45	0.017	1.37	0.146	0.04	0.937
Others	Reference		Reference		Reference		Reference		Reference	

Table 3 (continued)

Variable	Family caregiver burden		Physical-psychological burden		Spiritual burden		Daily-living burden		Economic burden	
	β	<i>p</i> value	β	<i>p</i> value	β	<i>p</i> value	β	<i>p</i> value	β	<i>p</i> value
Economic status										
≤ 20,000 NT dollars	− 1.20	0.770	− 1.04	0.550	− 0.66	0.492	− 0.48	0.610	0.99	0.305
> 20,000 NT dollars	Reference		Reference		Reference		Reference		Reference	
Comorbidity										
Yes	− 0.86	0.891	0.56	0.834	0.93	0.503	− 1.34	0.304	− 1.21	0.418
No	Reference		Reference		Reference		Reference		Reference	
Perceived disease severity	2.21	0.266	0.75	0.372	0.51	0.343	0.54	0.190	0.47	0.244
DNR signature										
Pre-PCCS	0.12	0.978	0.35	0.847	0.61	0.541	0.23	0.804	− 1.16	0.254
Post-PCCS	Reference		Reference		Reference		Reference		Reference	
Symptom distress	− 0.13	0.122	− 0.06	0.104	− 0.02	0.419	− 0.03	0.116	− 0.20	0.266
PPI	1.14	0.018	0.46	0.020	0.31	0.008	0.23	0.024	0.18	0.072

GEE generalized estimating equation, PCCS palliative care consultation service, PPI palliative prognostic index

As expected, there were no significant differences in FCB between CFC and NCFC over time following PCCS in this study. Similar to the previous findings [22], the results showed no significant differences in caregiver burden in end-of-life

Table 4 GEE model of family caregiver burden between terminal CFC and NCFC pre-, 7 days, and 14 days following PCCS

	Family caregiver burden		Physical-psychological burden		Spiritual burden		Daily-living burden		Economic burden	
	β	<i>p</i> value	β	<i>p</i> value	β	<i>p</i> value	β	<i>p</i> value	β	<i>p</i> value
Time × family caregiver										
Pre-PCCS										
CFC/NCFC	Reference		Reference		Reference		Reference		Reference	
7 days following PCCS										
CFC/NCFC	− 1.74	0.811	− 0.83	0.800	− 0.26	0.915	− 0.54	0.714	0.16	0.893
14 days following PCCS										
CFC/NCFC	0.74	0.947	− 0.03	0.995	− 0.81	0.820	0.77	0.744	− 0.84	0.560
Time										
Pre-PCCS	Reference		Reference		Reference		Reference		Reference	
7 days following PCCS	− 1.24	0.825	− 0.59	0.826	− 0.24	0.907	− 0.25	0.828	− 0.46	0.516
14 days following PCCS	− 13.25	0.144	− 5.60	0.180	− 2.00	0.529	− 3.02	0.095	− 1.58	0.023
Family caregiver										
CFC	1.97	0.706	− 0.10	0.967	− 0.14	0.919	0.44	0.697	1.87	0.111
NCFC	Reference		Reference		Reference		Reference		Reference	
Patient's religious belief										
No	4.56	0.313	3.79	0.020	0.19	0.867	0.07	0.947	0.45	0.678
Yes	Reference		Reference		Reference		Reference		Reference	
Patient's economic source										
Self	6.96	0.090	2.51	0.112	2.66	0.005	1.55	0.081	0.04	0.969
Others	Reference		Reference		Reference		Reference		Reference	
PPI	1.18	0.010	0.41	0.026	0.32	0.003	0.25	0.009	0.22	0.020

Model was adjusted with significant variables of univariate GEE analysis, including patient's religious belief, patient's economic source, and PPI
GEE generalized estimating equation, PCCS palliative care consultation service, CFC cancer family caregiver, NCFC non-cancer family caregiver, PPI palliative prognostic index

Table 5 GEE model of family caregiver burden in family caregivers of terminal patients pre-, 7 days, and 14 days following PCCS

Variables	Family caregiver burden		Physical-psychological burden		Spiritual burden		Daily-living burden		Economic burden	
	β	<i>p</i> value	β	<i>p</i> value	β	<i>p</i> value	β	<i>p</i> value	β	<i>p</i> value
Time										
Pre-PCCS	Reference		Reference		Reference		Reference		Reference	
7 days following PCCS	-2.46	0.491	-1.14	0.463	-0.40	0.715	-0.63	0.378	-0.39	0.553
14 days following PCCS	-12.67	0.013	-5.62	0.022	-2.59	0.055	-2.45	0.043	-2.15	0.019
Patient's religious belief										
No	4.42	0.332	3.76	0.019	0.19	0.862	0.01	0.990	0.37	0.748
Yes	Reference		Reference		Reference		Reference		Reference	
Patient's economic source										
Self	7.08	0.082	2.50	0.111	2.66	0.005	1.57	0.072	0.23	0.824
Others	Reference		Reference		Reference		Reference		Reference	
PPI	1.14	0.013	0.42	0.024	0.33	0.002	0.25	0.014	0.18	0.078

Model was adjusted with significant variables of univariate GEE analysis, including patient's religious belief, patient's economic source, and PPI
GEE generalized estimating equation, *PCCS* palliative care consultation service, *PPI* palliative prognostic index

care between patients with advanced cancer and those with dementia. Nevertheless, it was a cross-sectional comparative study and did not focus on the effectiveness of PCCS. This study was designed based on the hypothesis that PCCS is important in end-of-life care with respect to both CFC and NCFC. Caregiver burden may have been reduced as family caregivers could improve their caretaking skills and receive physical, psychological, social, and spiritual support from the PCCS team members [15].

The study showed that the caregivers of patients with religious beliefs had a lower physical-psychological burden over time after availing PCCS versus caregivers of patients without religious beliefs. This result was similar to Lai et al.'s study [23]. The intrinsic spirituality is a negative predictor of emotional burden. Higher levels of intrinsic spirituality that is protected against emotional distress are linked to providing assistance in terminal CFC. A systematic review indicated that religious belief and practice should pertain to end-of-life care [24]. Religious belief was found to be positively associated with spiritual well-being and negatively associated with physical suffering. It is also a protective factor that can enhance self-worth and close relationships as well as help caregivers cope with their loved one's illness [25, 26]. In addition, caregivers who are religious practitioners were found to be more likely to have a positive perception of their role [27]. These two domains of spirituality, namely, self-discipline and meanness-generosity, mediate the relationship between caregiver burden and psychological well-being of caregivers [28].

Similar to the findings of previous studies [29–31], the data revealed that caregivers of patients without financial support had a higher spiritual burden after PCCS than the caregivers of patients with financial support. There are two possible

explanations for such findings. First, in Taiwanese culture, taking care of and providing financial support to one's parents are social norms [32]. However, the average age of caregivers in the present study is around 50 years old, which is when people are most burdened by other family responsibilities, such as caring for one's children. Indeed, a cross-sectional study conducted on Korean terminal CFC indicated that financial concerns were more likely to occur in married family caregivers [33]. Second, the role of caregiver is also considered to be the duty of a woman in the family, especially when the woman's income is low. This may be because high-income women will either spend money on outsourcing a caregiver, or refuse to take care of a patient due to their having a high-paying job [34].

PPI that is the survival prediction of terminally ill cancer patients was the most important predictor in family caregiver burden, including physical-psychological, spiritual, and daily-living burden over time following PCCS in the present study. The higher the PPI score among the terminally ill patients, the worse their physical functional status, oral intake, edema, dyspnea at rest, or delirium [18]. Similar to the findings of previous studies [35–37], higher family caregiver burden was found to be strongly associated with patients' disease progression and decline in physical and mental functioning. This may be due to the increased number and intensity of care-giving tasks. Therefore, the better the caregiver's social resources are, the lower the caregiver burden is. When caregivers can get help from their relatives, friends, or other people, they can cope more successfully and attain better psychosocial-spiritual outcomes [38].

This study had several strengths. First, we used a prospective longitudinal design. Second, we recruited family

caregivers of both terminally ill cancer and non-cancer patients who received PCCS. However, the limitations of this study cannot be ignored. First, the participants were selected from a small population because one of the inclusion criteria for sample selection was that patients must have clear consciousness and should be ready to receive PCCS. Therefore, these results cannot be generalized to the family caregivers of all terminally ill patients, and the FCB may be underestimated. Second, we did not recruit patients and caregivers who had not received PCCS. As a result, caregiver burden among them was unknown. Finally, the current clinical practice of PCCS in Taiwan does not allow for a follow-up on family caregiver burden after the termination of PCCS. Thus, the long-term effects of PCCS on family caregiver burden were unknown.

Based on the study's limitations, future research directions are suggested. First, studies with a larger sample size encompassing various medical centers or hospitals are needed to increase the applicability and generalizability of findings. Second, a prospective cohort study comparing FCB in family caregivers with or without PCCS is recommended to understand the trends in caregiver burden of these two groups. Finally, the continuity of care after a patient's death is the core concept of palliative care, and we therefore suggest that clinical practice and future studies should continuously follow up on caregiver burden after the termination of PCCS.

Conclusion

The present study showed that PCCS can improve family caregiver burden not only in CFC but also in NCFC over time following PCCS. PPI of patients was the key predictor of FCB over time following PCCS. We suggest that PCCS should be used more widely in supporting family caregivers to reduce their burden.

Acknowledgments The authors are very grateful to the participant in the study. We also thank the staff of the Department of Nursing for their dedicated help and assistance with participant recruitment.

Funding information This study was supported by the Tri-Service General Hospital (TSGH-C106-127) and Ministry of National Defense-Medical Affairs Bureau (MAB-106-062).

Compliance with ethical standards

Conflict of interest The authors declare that they have no competing interests.

References

1. Ministry of Health and Welfare (2018) 2017 Statistics of causes of death. <https://dep.mohw.gov.tw/DOS/cp-3960-41756-113.html>. Accessed 26 June 2018
2. Wang FTY (2011) Reforming long term care through the movement of family caregivers. Taiwan: A radical quarterly in social studies 85:397–414
3. Wagner CD, Tanmoy Das L, Bigatti SM, Storniolo AM (2011) Characterizing burden, caregiving benefits, and psychological distress of husbands of breast cancer patients during treatment and beyond. *Cancer Nurs* 34:E21–E30
4. Liu MY, Liu HE, Wan HM, Tsay PK, Jane SW, Lin YH (2015) The efficacy of a hospice shared-care model on the care overload of primary caregivers of terminal-stage cancer patients. *J Nurs Heal Res* 11(4):257–266. <https://doi.org/10.6225/jnhr.11.4.257>
5. Naoki Y, Matsuda Y, Maeda I, Kamino H, Kozaki Y, Tokoro A, Maki N, Takada M (2018) Association between family satisfaction and caregiver burden in cancer patients receiving outreach palliative care at home. *Palliat Support Care* 16:260–268
6. Yamamoto S, Arao H, Masutani E, Aoki M, Kishino M, Morita T, Shima Y, Kizawa Y, Tsuneto S, Aoyama M, Miyashita M (2017) Decision making regarding the place of end-of-life cancer care: the burden on bereaved families and related factors. *J Pain Symptom Manag* 53:862–870
7. Health Promotion Administration (2018) Hospice care. <https://www.hpa.gov.tw/Pages/List.aspx?nodeid=210>. Accessed 26 June 2018
8. Minetti A (2011) Working together. An interdisciplinary approach to dying patients in a palliative care unit. *J Med Ethics* 37:715–718
9. Loke SS, Rau KM, Huang CF (2011) Impact of combined hospice care on terminal cancer patients. *J Palliat Med* 14:683–687
10. Chou WC, Hung YS, Kao CY, Su PJ, Hsieh CH, Chen JS, Liaw CT, Lin YC, Liaw CC, Wang HM (2013) Impact of palliative care consultative service on disease awareness for patients with terminal cancer. *Support Care Cancer* 21:1973–1981
11. Chang PM, Liu YY, Chao TC, Lin HL, Chen MB, Chen PM, Chiou TJ (2010) A new hospice consulting system for terminal cancer patients in transferring to post-acute care options in Taiwan. *Eur J Cancer Care* 19(2):267–272
12. Gade G, Venohr I, Conner D, McGrady K, Beane J, Richardson RH, Williams MP, Liberson M, Blum M, Della Penna R (2008) Impact of an inpatient palliative care team: a randomized control trial. *J Palliat Med* 11:180–190
13. Guerriere D, Husain A, Zagorski B, Marshall D, Seow H, Brazil K, Kennedy J, Burns S, Brooks H, Coyte PC (2016) Predictors of caregiver burden across the home-based palliative care trajectory in Ontario, Canada. *Health Soc Care Community* 24:428–438
14. Wu LF, Chu CM, Chen YG, Ho CL, Pan HH (2016) Relationship between palliative care consultation service and end-of-life outcomes. *Support Care Cancer* 24:53–60
15. Tabler J, Utz RL, Ellington L, Reblin M, Caserta M, Clayton M, Lund D (2015) Missed opportunity: hospice care and the family. *J Soc Work End Life Palliat Care* 11:224–243
16. McCorkle R, Young K (1978) Development of a symptom distress scale. *Cancer Nurs* 1:373–378
17. Lai YH (1998) Symptom distress and home care needs in patients receiving chemotherapy in an outpatient setting. *Nursing Study* 6: 279–289
18. Morita T, Tsunoda J, Inoue S, Chihara S (1999) The Palliative Prognostic Index: a scoring system for survival prediction of terminally ill cancer patients. *Support Care Cancer* 7:128–133
19. Hong SH, Lin SY (2010) A pilot study on developing a Family Caregiver Burden Scale for family caregivers of the terminal cancer patients. *Tzu Chi Nurs J* 9:66–77
20. Salazar A, Ojeda B, Duenas M, Fernandez F, Failde I (2016) Simple generalized estimating equations (GEEs) and weighted generalized estimating equations (WGEEs) in longitudinal studies with dropouts: guidelines and implementation in R. *Stat Med* 35(19):3424–3448
21. Krug K, Miksch A, Peters-Klimm F, Engeser P, Szecsenyi J (2016) Correlation between patient quality of life in palliative care and

- burden of their family caregivers: a prospective observational cohort study. *BMC Palliat Care* 15:4
22. Costa-Requena G, Espinosa Val MC, Cristofol R (2015) Caregiver burden in end-of-life care: advanced cancer and final stage of dementia. *Palliat Support Care* 13:583–589
 23. Lai C, Luciani M, Di Mario C, Galli F, Morelli E, Ginobbi P, Aceto P, Lombardo L (2018) Psychological impairments burden and spirituality in caregivers of terminally ill cancer patients. *Eur J Cancer Care* 27(1). <https://doi.org/10.1111/ecc.12674>
 24. Chakraborty R, El-Jawahri AR, Litzow MR, Syrjala KL, Parnes AD, Hashmi SK (2017) A systematic review of religious beliefs about major end-of-life issues in the five major world religions. *Palliat Support Care* 15:609–622
 25. Lo C, Zimmermann C, Gagliese L, Li M, Rodin G (2011) Sources of spiritual well-being in advanced cancer. *BMJ Support Palliat Care* 1:149–153
 26. Delgado-Guay MO, Parsons HA, Hui D, De la Cruz MG, Thorney S, Bruera E (2013) Spirituality, religiosity, and spiritual pain among caregivers of patients with advanced cancer. *Am J Hosp Palliat Care* 30:455–461
 27. Park CH, Shin DW, Choi JY, Kang J, Baek YJ, Mo HN, Lee MS, Park SJ, Park SM, Park S (2012) Determinants of the burden and positivity of family caregivers of terminally ill cancer patients in Korea. *Psychooncology* 21:282–290
 28. Anum J, Dasti R (2016) Caregiver burden, spirituality, and psychological well-being of parents having children with thalassemia. *J Relig Health* 55:941–955
 29. Tilden VP, Tolle SW, Drach LL, Perrin NA (2004) Out-of-hospital death: advance care planning, decedent symptoms, and caregiver burden. *J Am Geriatr Soc* 52(4):532–539
 30. Adelman RD, Tmanova LL, Delgado D, Dion S, Lachs MS (2014) Caregiver burden: a clinical review. *JAMA* 311(10):1052–1060
 31. Ku LE, Chang SM, Pai MC, Hsieh HM (2019) Predictors of caregiver burden and care costs for older persons with dementia in Taiwan. *Int Psychogeriatr* 31(6):885–894
 32. Chappell NL, Kusch K (2007) The gendered nature of filial piety—a study among Chinese Canadians. *J Cross Cult Gerontol* 22(1):29–45
 33. Choi YS, Hwang SW, Hwang IC, Lee YJ, Kim YS, Kim HM, Youn CH, Ahn HY, Koh SJ (2016) Factors associated with quality of life among family caregivers of terminally ill cancer patients. *Psychooncology* 25:217–224
 34. Neufeld A, Harrison MJ, Hughes KD, Spitzer D, Stewart MJ (2001) Participation of immigrant women family caregivers in qualitative research. *West J Nurs Res* 23(6):575–591
 35. Agren S, Evangelista L, Stromberg A (2010) Do partners of patients with chronic heart failure experience caregiver burden? *Eur J Cardiovasc Nurs* 9:254–262
 36. Grunfeld E, Coyle D, Whelan T, Clinch J, Reyno L, Earle CC, Willan A, Viola R, Coristine M, Janz T, Glossop R (2004) Family caregiver burden: results of a longitudinal study of breast cancer patients and their principal caregivers. *CMAJ* 170:1795–1801
 37. Dumont S, Turgeon J, Allard P, Gagnon P, Charbonneau C, Vézina L (2006) Caring for a loved one with advanced cancer: determinants of psychological distress in family caregivers. *J Palliat Med* 9:912–921
 38. Burton AM, Sautter JM, Tulsy JA, Lindquist JH, Hays JC, Olsen MK, Zimmerman SI, Steinhauer KE (2012) Burden and well-being among a diverse sample of cancer, congestive heart failure, and chronic obstructive pulmonary disease caregivers. *J Pain Symptom Manag* 44:410–420

Publisher's note Springer Nature remains neutral with regard to jurisdictional claims in published maps and institutional affiliations.