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Caregiver burden of cancer patients undergoing palliative PTBD: an investigation of patient and caregiver factors

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Abstract

Purpose The purpose of this study was to explore caregiver burden and its influencing factors in cancer patients undergoing palliative PTBD from both caregiver and patient perspectives.

Methods A cross-sectional study was conducted on caregiver-patient dyads who underwent palliative percutaneous transhepatic biliary drainage (PTBD) from January to December 2023 at a tertiary hospital in western China. The Zarit Caregiver Burden Interview (ZBI), the Chinese version of the Family Resilience Assessment Scale (FRAS), the Self-Perceived Burden Scale (SPBS), and the Hospital Anxiety and Depression Scale (HADS) were used to assess outcome variables. Sociodemographic data and PTBD-related characteristics were also collected. Multiple linear regression was conducted to identify the influencing factors of caregiver burden.

Results A total of 185 caregiver-patient dyads were included in this study. The participants had a mean age of 51.6 years, and 68.6% were female. The median ZBI score was 58.7, with 47.5% of caregivers experiencing severe burden. Caregivers' daily time spent on caregiving, anxiety ($\beta = 1.20$, $p = 0.001$), depression ($\beta = 0.86$, $p = 0.009$), and family resilience ($\beta = -0.11$, $p = 0.016$) were found to be influencing factors of caregiver burden. Additionally, patient age ($\beta = 0.20$, $p < 0.001$), female sex ($\beta = 3.61$, $p = 0.010$), having more than one tube ($\beta = 4.22$, $p = 0.003$), and the tube maintenance institution were identified as influencing factors of caregiver burden.

Conclusion Caregivers of cancer patients undergoing palliative PTBD had a considerable burden, which was influenced by factors from both the caregiver and patient perspectives. It is imperative for healthcare providers to develop interventions that target the modifiable influencing factors identified to support these caregivers effectively.

Keywords PTBD, Cancer, Caregiver burden, Cross-sectional study, Influencing factors

Introduction

Palliative percutaneous transhepatic biliary drainage (PTBD) is a common procedure used to relieve malignant obstructive jaundice caused by advanced malignancies such as unresectable cholangiocarcinoma and pancreatic carcinoma [1, 2]. However, palliative PTBD requires the use of an external drainage tube, making patients susceptible to postoperative complications, including pain, bleeding, drainage dislodgement, cholangitis, and acute pancreatitis [3, 4]. As a result, cancer patients who undergo palliative PTBD require regular tube maintenance and clinic appointments accompanied by their caregivers. At the same time, these caregivers also take on the responsibility for providing physical, psychological, and financial support during the long-term treatment and rehabilitation of these patients [5, 6]. Given the diverse needs of cancer patients undergoing palliative

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PTBD, caregivers are often at risk of experiencing a significant caregiver burden [7].

Caregiver burden is defined as the extent to which caregivers feel that their emotional and physical health, social life, and financial status are affected by providing care [8]. The prevalence of caregiver burden in individuals providing care for cancer patients ranges from 30.7% to 50.0% [9–11]. The total caregiver burden when providing care for cancer patients may remain stable at a high level and not decrease over time [12]. Caregiver burden has adverse effects on caregivers' health status, including an increased risk of mortality [13], increased anxiety and depression symptoms [14, 15], impaired social connections [16], and financial loss [10]. These adverse outcomes reduce caregivers' capacity for providing qualified and optimal care for cancer patients, resulting in negative impacts on patients themselves [17, 18].

Caregiver burden is a multidimensional issue influenced by a wide variety of factors. Previous studies have identified several risk factors for caregiver burden from the perspectives of both caregivers and cancer patients. Caregiver characteristics such as age, sex, education level, caregiving hours, duration of caregiving, depression symptoms, and resilience have been found to be influencing factors of caregiver burden when providing care for cancer patients [9, 10, 19, 20]. Patient characteristics such as age, stage of cancer, treatment strategies, care settings, and health status also contribute to caregiver burden [10, 19, 21]. Although the caregiver burden of cancer patients has been extensively documented in previous literature, there is a paucity of data on the caregiver burden in the context of cancer patients undergoing palliative PTBD, particularly in low- to middle-income countries. Additionally, many previous studies that have identified risk factors for caregiver burden in cancer patients have yielded low to moderate R-squared values, ranging from 0.243 to 0.40 [10, 19, 21, 22]. This suggests that there may be additional key risk factors that have yet to be discovered.

Therefore, this study aimed to investigate the caregiver burden of cancer patients undergoing palliative PTBD and identify the factors contributing to this burden. By examining the experiences of caregivers, this study seeks to provide valuable insights into the challenges faced by caregivers of cancer patients undergoing PTBD and help with the development of tailored support services for this vulnerable population.

Method

Study design

This was a cross-sectional study investigating the caregiver burden of cancer patients undergoing palliative PTBD and identifying its influencing factors from both caregiver and patient perspectives.

Setting and sample

A convenience sampling method was used to recruit cancer patients, who underwent palliative PTBD from January to December 2023 at a tertiary hospital in Sichuan Province, western China, and their caregivers. The inclusion criteria for patients were as follows: (1) aged 18 years or older; (2) diagnosed with primary periampullary carcinomas, primary liver cancers (including hepatocellular carcinoma and intrahepatic cholangiocarcinoma), and metastatic cancers involving the biliary system or other abdominal organs; (3) received palliative PTBD; and (4) had at least one informal caregiver. Patients were excluded if they had moderate to severe cognitive impairment. The inclusion criteria for caregivers were as follows: (1) aged 18 years or older; and (2) served as the primary caregiver without payment. If more than one caregiver existed at the same time, only those who spent more time on caring were included.

The sample size was estimated using PASS version 16 (NCSS LLC., Utah, USA). The parameters were set as follows: a medium effect size (Cohen's $f^2 = 0.15$), a significance level of $\alpha = 0.05$, and a statistical power of $1\text{-}\beta = 0.90$. Based on a multiple linear regression model with 20 predictor variables and 4 control variables (age and sex of both caregivers and patients), the minimum required sample size was calculated to be 155. Considering a 10% nonresponse rate, the final sample size was determined to be 171.

Measurement

Caregivers'sociodemographic data, including age, sex, years of education, marital status, monthly income, presence of diabetes mellitus and hypertension, and employment status, were assessed using a self-designed questionnaire. Care-related characteristics such as time spent on caring per day and whether the caregiver lived with the patients were also collected. The self-designed questionnaire also included patients' sociodemographic data, specifically age, sex, and years of education, as well as PTBD-related characteristics such as diagnosis, number of tubes, experience with tube placement, duration of tube placement, the tube maintenance institution, and the easy access to tube maintenance or not (within a 30-min drive).

The Zarit Caregiver Burden Interview (ZBI), developed by Zarit, Todd and Zarit [23], was used to evaluate caregiver burden. This scale consists of 22 items rated on a five-point Likert scale from 0 (no burden) to 4 (maximum burden) for each item. The total scores on the ZBI range from 0 to 88, with higher scores indicating a greater burden. This scale has demonstrated good internal consistency in the Chinese population, with a Cronbach's alpha coefficient of 0.87 [24].

The Chinese version of the Family Resilience Assessment Scale (FRAS), developed by Dai [25], was used to evaluate caregivers' family resilience. The FRAS comprises two subscales: family faith and family strength, with a total of 49 items. The family faith subscale includes four dimensions including dilemma interpretation (7 items), forward-looking (6 items), and life excellence (4 items). The family strength subscale consists of seven dimensions, including problem-solving (6 items), intimacy and harmony (4 items), social support (4 items), order (3 items), emotional sharing (4 items), clear communication (5 items), and cooperation and coordination (6 items). The respondents rate each item on a five-point Likert scale, ranging from 1 (strongly disagree) to 5 (strongly agree). The total scores range from 49 to 245, where higher scores reflect greater family resilience. This scale has shown good internal consistency in the Chinese population, with a Cronbach's alpha coefficient of 0.912 [25].

The Self-Perceived Burden Scale (SPBS), developed by Cousineau, McDowell [26], was used to assess patients' self-perceived burden. The SPBS consists of three dimensions: physical, emotional, and financial burden, totaling 10 items. This scale is scored using a five-point Likert scale ranging from 1 to 5, with higher scores indicating a greater self-perceived burden. Total scores are classified as no (< 20), mild (20–29), moderate (30–39), and severe (≥ 40) self-perceived burden. The internal consistency of this scale is good in Chinese cancer patients, with a Cronbach's alpha coefficient of 0.91 [27].

The Hospital Anxiety and Depression Scale (HADS), developed by Zigmond and Snaith [28], was used to assess anxiety and depression symptoms in both caregivers and patients. This scale consists of 14 items, with 7 items accounting for anxiety and 7 items accounting for depression. Each item is scored using a four-point Likert scale, resulting in a total score ranging from 0 to 21 for anxiety and depression, respectively. The total scores are categorized as follows: no (0–7), mild (8–10), moderate (11–14), and severe (15–21) anxiety/depression. This scale has shown good internal consistency among Chinese cancer patients, with a Cronbach's α of 0.919 [29].

Data collection

Cancer patients who underwent palliative PTBD at the Department of Ultrasound Medicine from January to December 2023, as well as their caregivers, were screened for inclusion in the study. Patient-caregiver dyads who met the eligibility criteria and returned to clinic appointments were invited to participate. Written informed consent was obtained from all participants, and the data were collected through face-to-face interview and a review of the Hospital Information System (HIS). Each interview with patient-caregiver dyads lasted approximately 20 to 30 min. For patients who were unable to attend clinic appointments, telephone calls were made to invite them and their caregivers to participate. If they agreed, a video call using a social media application such as WeChat was conducted to complete the interview.

Data analysis

Data analyses were conducted using R software v4.3.1. Continuous variables were described as the mean and standard deviation (SD) if they were normally distributed; otherwise, they were described as the median and interquartile range (IQR). Categorical variables were summarized using frequency and percentage. Univariate analyses, including Student's t-test, one-way analysis of variance, the Mann–Whitney U test, Pearson correlation analysis, and Spearman correlation analysis, were performed to select candidate influencing factors of caregiver burden ($p < 0.1$). Multiple linear regression analysis was used to identify influencing factors of caregiver burden using the Akaike information criterion. Multicollinearity was tested using the variance inflation factor (VIF). If variables had a high VIF value of 10 or more than 10, only one variable were remained for the regression analysis. Two-tailed p value <0.05 was considered to indicate statistical significance in all analyses.

Results

Baseline characteristics of the included caregivers and patients

Table 1 shows the baseline characteristics of the caregivers and patients. The study included 185 patient-caregiver dyads. The caregivers were 51.6 years old on average, with 68.6% being female. Among the caregivers, 61.6% were spouses, and 89.7% lived with patients. Up to 73.5% of the caregivers spent more than four hours every day on caring for patients. The patients had an average age of 58.7 years and 34.6% were female. Among the patients, 48.6% had biliary tract/gallbladder cancer, 42.7% had experienced PTBD, and 21.1% had more than one tube. 58.4% of the patients received palliative PTBD within three months, and more than half received tube maintenance services from the hospital.

Outcome measurement of the caregivers and patients

Table 2 shows the caregiver burden and other outcomes for both caregivers and patients. In terms of caregivers, the average ZBI score was 58.7, with 47.5% reporting severe burden. A total of 4.8% and 24.3% of caregivers reported moderate to severe anxiety and depression,

Table 1 Baseline characteristics of the included caregivers and patients ($N = 185$ pairs)

Characteristics	Mean ± SD/N (%)
Caregivers	
Age	51.6 ± 8.7
Sex (female)	127 (68.6)
Education years (≤ 12 years)	138 (74.6)
Marital status (married)	182 (98.4)
Monthly income	
< 3000	64 (34.6)
3000–5000	108 (58.4)
≥ 5000	13 (7.0)
Diabetes mellitus (yes)	15 (8.1)
Hypertension (yes)	66 (35.7)
Relationship with patients	
Offsprings	61 (33.0)
Spouses	114 (61.6)
Others	10 (5.4)
Employment status (employed)	146 (78.9)
Time spent caring per day	
0–4 h	49 (26.5)
5–8 h	97 (52.4)
> 8 h	39 (21.1)
Living with patients (yes)	166 (89.7)
Patients	
Age	58.7 ± 12.1
Sex (female)	64 (34.6)
Education years (≤ 12 years)	159 (85.9)
Diagnose	
Biliary tract/gallbladder cancer	90 (48.6)
Pancreatic cancer	44 (23.8)
Liver cancer	42 (22.7)
Others	9 (4.9)
More than one tube (yes)	39 (21.1)
Experience with tube placement (yes)	79 (42.7)
Duration of tube placement	
0–3 months	108 (58.4)
4–6 months	61 (33.0)
> 6 months	16 (8.6)
Tube maintenance institution	
Home self-caring	78 (42.2)
Community	6 (3.2)
Hospital	101 (54.6)
Easy access to tube maintenance (yes)	8 (4.3)

SD: standard deviation

Table 2 Outcome measurement of the caregivers and patients

Variables	Median (IQR)/N (%)
Caregivers	
ZBI [Mean ± SD]	58.7 ± 10.1
No	0 (0)
Mild	4 (2.2)
Moderate	93 (50.3)
Severe	88 (47.5)
HAD-A	6.0 (5.0, 8.0)
No	128 (69.2)
Mild	48 (25.9)
Moderate	8 (4.3)
Severe	1 (0.5)
HAD-D	9.0 (7.0, 10.0)
No	61 (33.0)
Mild	79 (42.7)
Moderate	45 (24.3)
Severe	0 (0)
FRAS	183.0 (175.0, 190.0)
Patients	
SPBS	25.0 (21.0, 28.0)
No	33 (17.8)
Moderate	125 (67.6)
Severe	27 (14.6)
HAD-A	9.0 (7.0, 10.0)
No	52 (28.1)
Mild	88 (47.6)
Moderate	40 (21.6)
Severe	5 (2.7)
HAD-D	10.0 (8.0, 11.0)
No	34 (18.4)
Mild	87 (47.0)
Moderate	61 (33.0)
Severe	3 (1.6)

ZBI: Zarit Caregiver Burden Interview (< 20 [no],20–39 [mild], 40 ~ 59 [moderate], and ≥ 60 [severe]); HAD-A: Hospital Anxiety and Depression Scale-Anxiety (< 8 [no], 8–10 [mild], 11–14 [moderate], and 15–21 [severe]); HAD-D: Hospital Anxiety and Depression Scale-Depression (< 8 [no], 8–10 [mild], 11–14 [moderate], and 15–21 [severe]); FARS: Family Resilience Assessment Scale; SPBS: Self-perceived Burden Scale (< 20 [no], 20–29 [mild], 30–39 [moderate], and ≥ 40 [severe]); SD: standard deviation; IQR: interquartile range

respectively. The median FRAS score was 183.0 (175.0, 190.0). In terms of patients, the median SPBS was 25.0 (21.0, 28.0), with 82.2% reporting moderate to severe self-perceived burden. Moderate to severe anxiety and depression were reported by 24.3% and 34.6% of patients, respectively.

Univariate analysis of caregiver burden

Table 3 displays the results of univariate analysis of caregiver burden. Caregiver age ($r = 0.325$, $p < 0.001$), HAD-A ($r = 0.511$, $p < 0.001$), and HAD-D ($r = 0.463$, $p < 0.001$) were positively associated with caregiver burden, while FRAS scores ($r = -0.284$, $p < 0.001$) were negatively associated with caregiver burden. Caregiver

Table 3 Univariate analysis of caregiver burden

Caregiver				**Patients**			
Characteristics	**N (%)**	**ZBI**	**Statistics**	**Characteristics**	**N (%)**	**ZBI**	**Statistics**
Age [Mean ± SD]	51.6 ± 8.7	58.7 ± 10.1	R = 0.325***	Age	58.7 ± 12.1	58.7 ± 10.1	r = 0.242***
Sex				Sex			
Male	58 (31.3)	59.6 ± 11.8	t = 0.835	Male	121 (65.4)	57.0 (50.0, 64.0)	Z = − 2.887**
Female	127 (68.7)	58.3 ± 9.3		Female	64 (34.6)	62.5 (56.0, 68.0)	
Education years				Education years			
≤ 12 years	138 (74.6)	60.1 ± 9.6	t = 3.451***	≤ 12 years	159 (85.9)	59.6 ± 9.9	t = 2.996**
> 12 years	47 (25.4)	54.4 ± 10.4		> 12 years	26 (14.1)	53.3 ± 9.4	
Marital status				Diagnose			
Married	182 (98.4)	58.9 ± 10.0	t = 10.881***	Biliary tract/gallbladder cancer	90 (48.6)	58.7 ± 10.4	F = 0.561
Single	3 (1.6)	46.3 ± 1.5		Pancreatic cancer	44 (23.8)	59.8 ± 9.5	
Monthly income				Liver cancer	42 (22.7)	58.1 ± 8.9	
< 3000	64 (34.595)	63.8 ± 9.8	F = 15.822***	Others	9 (4.9)	55.3 ± 14.8	
3000–5000	108 (58.378)	56.4 ± 8.9		More than one tube			
> 5000	13 (7.027)	52.5 ± 11.2		No	146 (79.0)	57.4 ± 9.8	t = − 3.326**
Diabetes mellitus				Yes	39 (21.1)	63.3 ± 9.9	
No	170 (91.9)	58.0 ± 9.9	t = − 3.338**	Experience with tube placement			
Yes	15 (8.1)	66.8 ± 8.1		No	106 (57.3)	57.8 ± 9.3	t = − 1.385
Hypertension				Yes	79 (42.7)	59.9 ± 11.0	
No	119 (64.3)	56.8 ± 10.1	t = − 3.423***	Duration of tube placement			
Yes	66 (35.7)	62.0 ± 9.2		0–3 months	108 (58.4)	57.7 ± 10.0	F = 1.341
Relationship with patients				4–6 months	61 (33.0)	60.0 ± 8.9	
Offsprings	61 (33.0)	58.3 ± 10.6	F = 0.158	> 6 months	16 (8.6)	60.4 ± 14.4	
Spouses	114 (61.6)	59.0 ± 9.6		Tube maintenance institution			
Others	10 (5.4)	57.4 ± 13.1		Home self-caring	78 (42.2)	59.5 ± 10.0	F = 2.913*
Employment status				Community	6 (3.2)	49.3 ± 14.2	
Employed	146 (78.9)	58.0 ± 10.0	t = 1.820*	Hospital	101 (54.6)	58.6 ± 9.7	
Unemployed/retired	39 (21.1)	61.3 ± 10.2		Easy access to tube maintenance			
Time spent caring per day				No	177 (95.7)	58.9 ± 10.1	t = 1.238
0–4 h	49 (26.5)	54.0 ± 9.4	F = 16.036***	Yes	8 (4.3)	54.4 ± 8.8	
5–8 h	97 (52.4)	58.4 ± 9.1		SPBS [Median (IQR)]	25.0 (21.0, 28.0)	58.7 ± 10.1	r = 0.191**
> 8 h	39 (21.1)	65.4 ± 9.9		HAD-A [Median (IQR)]	9.0 (7.0, 10.0)	58.7 ± 10.1	r = − 0.059
Living with patients				HAD-D [Median (IQR)]	10.0 (8.0, 11.0)	58.7 ± 10.1	r = 0.001
No	19 (10.3)	51.8 ± 11.1	t = − 3.226**				
Yes	166 (89.7)	59.5 ± 9.7					
HAD-A [Median (IQR)]	6.0 (5.0, 8.0)	58.7 ± 10.1	r = 0.511***				
HAD-D [Median (IQR)]	9.0 (7.0, 10.0)	58.7 ± 10.1	r = 0.463***				
FRAS [Median (IQR)]	183.0 (175.0, 190.0)	58.7 ± 10.1	r = − 0.284***				

ZBI: Zarit Caregiver Burden Interview; HAD-A: Hospital Anxiety and Depression Scale-Anxiety; HAD-D: Hospital Anxiety and Depression Scale-Depression; FARS: Family Resilience Assessment Scale; SPBS: Self-perceived Burden Scale; SD: standard deviation; IQR: interquartile range; t: Student's t test; F: one-way analysis of variance; Z: Mann–Whitney U test; R: Pearson correlation analysis; r: Spearman correlation analysis; *: $p< 0.1$; **: $p< 0.05$; ***: $p< 0.001$

characteristics, including education years, marital status, monthly income, diabetes mellitus status, hypertension status, employment status, time spent on caring per day, and living with patients were also related to caregiver burden ($p< 0.1$). Patient age ($r= 0.242$, $p< 0.001$) and SPBS scores ($r=− 0.191$, $p< 0.01$) were positively associated with caregiver burden. Patient characteristics including sex, education years, more than one tube, and tube maintenance institution, were also related to caregiver burden ($p < 0.1$).

Multiple linear regression analysis of caregiver burden

Variables selected through univariate analysis were entered into the multiple linear regression model. Table S1 and Table S2 (Supplementary File) show the VIF statistics and detailed process of variable selection. Table 4 presents the final multiple linear regression model of caregiver burden. Caregiver HAD-A ($\beta = 1.20$, $p = 0.001$) and HAD-D ($\beta = 0.86$, $p = 0.009$) were positively associated with caregiver burden, whereas FARS scores ($\beta = -0.11$, $p = 0.016$) were negatively associated with caregiver burden. Additionally, caregivers' time spent on caring per day was found to be positively related to caregiver burden, indicating that longer caregiving hours were associated with greater burden. Furthermore, patient age ($\beta = 0.20$, $p < 0.001$), female sex ($\beta = 3.61$, $p = 0.010$), and the presence of more than one tube ($\beta = 4.22$, $p = 0.003$) were positively related to caregiver burden. The types of institution where patients received tube maintenance were also related to caregiver burden. Collectively, these variables from both caregivers and patients explained 49% of all variance in caregiver burden.

Table 4 Multiple linear regression analysis of caregiver burden

Variables	Std.β	95% CI	*p*	Adj.R^2
Caregivers' characteristics				0.49
Age	0.11	− 0.05, 0.27	0.169	
Sex				
Male	-	-	-	
Female	− 0.26	− 3.04, 2.52	0.855	
Education years				
≤ 12 years	-	-	-	
> 12 years	2.18	− 0.92, 5.28	0.167	
Time spent caring per day				
0–4 h	-	-	-	
5–8 h	3.35	0.51, 6.19	0.021	
> 8 h	5.43	1.83, 9.04	0.003	
Living with patients				
No	-	-	-	
Yes	2.99	− 0.98, 6.96	0.139	
HAD-A	1.20	0.58, 1.82	0.001	
HAD-D	0.86	0.22, 1.50	0.009	
FARS	− 0.11	− 0.20, − 0.02	0.016	
Patients' characteristics				
Age	0.20	0.11, 0.30	< 0.001	
Sex				
Male	-	-	-	
Female	3.61	0.89, 6.33	0.010	
More than one tube				
No	-	-	-	
Yes	4.22	1.47, 6.98	0.003	
Tube maintenance institution				
Home self-caring	-	-	-	
Community	− 7.06	− 13.40, − 0.71	0.030	
Hospital	− 0.90	− 3.18, 1.38	0.437	

HAD-A: Hospital Anxiety and Depression Scale-Anxiety; HAD-D: Hospital Anxiety and Depression Scale-Depression; FARS: Family Resilience Assessment Scale; SPBS: Self-perceived Burden Scale

Discussion

This study revealed that caregiver burden was prominent among those caring for cancer patients receiving palliative PTBD. Caregivers'anxiety, depression, time spent on caring per day, and family resilience were influencing factors of caregiver burden, along with patient age, female sex, the presence of more than one tube, as well as the tube maintenance institution.

It was not surprising to find that 47.5% of the caregivers providing care for cancer patients receiving palliative PTBD reported severe burden. This result is consistent with previous findings that revealed a significant proportion of caregiver burden when caring for cancer patients [9, 10]. In fact, cancer patients'care demands often emerge without warning signs, and caregivers are typically unprepared and lack prior experience to cope, resulting in physical and psychological distress [30]. Additionally, in China, family members typically serve as informal caregivers, providing physical, emotional, and financial support for cancer patients. It is extremely challenging to balance cancer care tasks with family routines in the early stages of diagnosis. Furthermore, cancer treatment and care can be costly, posing a major challenge for caregivers, especially among populations with low incomes [31]. For cancer patients undergoing palliative PTBD, care tasks are more complex and require additional financial support, inevitably leading to a greater caregiver burden. Therefore, healthcare providers and policymakers should pay more attention to caregiver burden and develop integrated strategies, such as PTBD-related skill education, psychological support, and insurance coverage, to alleviate this burden.

This study found that caregivers who spent more time on caregiving per day experienced a heavier burden. This finding confirms a previous result reported by Unsar [19]. The reason may be that caregivers who spend more time caring for cancer patients with palliative PTBD bear greater caregiving workload and participate in fewer personally social activities, ultimately leading to a greater burden. Furthermore, caregivers who devote more time to patient care are more likely to experience unemployment and financial loss, factors that are known to be associated with caregiver burden [32]. In addition to the complexity of caregiving activities, the lack of skills and knowledge to provide effective care may also contribute to caregiver burden. More than half of caregivers feel overwhelmed by the caregiving tasks they are required to handle, as reported by Girgis, Lambert [33]. Therefore, a training program for caregivers to enhance their ability to care for cancer patients undergoing palliative PTBD may be helpful for caregivers. In this study, caregivers'anxiety and depression symptoms were identified as critical risk factors for caregiver burden. As shown in Table 4, both anxiety (HAD-A: $\beta = 1.20$, $p = 0.001$) and depression (HAD-D: $\beta = 0.86$, $p = 0.009$) were independently associated with increased burden, reflecting both acute stress and chronic emotional exhaustion, which is particularly relevant in the context of care for palliative PTBD patients. Despite this, approximately 50% of caregivers of cancer patients do not seek psychological help, even when meeting the diagnostic criteria for psychiatric disorders [34], further exacerbating the caregiver burden. Therefore, it is an urgent need to provide routine anxiety and depression screening for caregivers of patients receiving palliative PTBD, as early identification could facilitate timely psychological support and alleviate long-term strain. In this study, family resilience (FARS) emerged as a significant protective factor against caregiver burden ($\beta = -0.11$, $p = 0.016$), indicating that a higher FARS score was associated with lower burden. This finding aligns with previous studies [22, 35], which have highlighted the role of family resilience as the positive capacity of a family to adapt to adverse life events or significant stressors [35]. Caregivers with higher resilience levels often experience reduced depression, improved overall health, and enhanced social support [36], all of which contribute to better burden-bearing abilities. Therefore, family resilience may play a critical role in alleviating burden for caregivers of palliative PTBD patient. Implementing family-centered interventions, such as psychoeducational workshops, peer support groups, or family counseling sessions, may mitigate caregiver burden by enhancing adaptive capacities and fostering supportive family dynamics.

This study revealed that older patients were more likely to bring up a greater caregiver burden. It is known that the rate of ADL (activity of daily living) disability increases with age [37]. Thus, caring for older cancer patients requires more effort from caregivers to assist with daily living tasks such as hygiene, mobility, and feeding. These additional responsibilities clearly contribute to the increased caregiver burden. Additionally, in this study, we observed that caregivers of female cancer patients undergoing palliative PTBD experienced a greater burden. Bektas and Demir [38] reported that female cancer patients were more likely to exhibit symptoms of depression, which was found to be related to caregivers'perceived burden through the patient-caregiver dyad model [18]. This finding suggests that healthcare providers should pay more attention to caregivers providing care for female cancer patients undergoing palliative PTBD. Moreover, this study revealed that having more than one tube increased caregiver burden. On the one hand, more tubes directly increase caregivers'caring time and workload, both of which contribute to caregiver burden [19]. On the other hand, cancer patients who receive multiple PTBD tubes typically suffer from a greater symptom burden related to biliary obstruction. According to a previous report by Dong, He [17], patients' symptom burden is positively related to caregiving burden. Interestingly, we found that cancer patients with palliative PTBD who carried out their routine tube maintenance at community health service centers placed less strain on caregivers than those who received home-based self-care. However, caregivers of patients who received tube maintenance from hospitals did not experience a reduction in caregiver burden. One possible explanation is that community health service centers provide more convenient tube maintenance services than hospitals, especially for patients with an exposed PTBD tube that affects mobility, clothing, and self-image. As a result, it is necessary to expand the scope and capacity of services in Chinese community health care centers, as only 3.2% of patients reported using community health services in our study.

Limitations

There are several limitations in this study. First, we only recruited participants from western China using a convenience sampling method, which may restrict the generalizability of our findings. Second, while our cross-sectional design identified significant associations between caregiver burden and factors such as anxiety, depression, and family resilience, the temporal sequence of these relationships remains unclear. Future longitudinal studies are needed to explore causality and control for potential confounding factors. Third, the proportion of patients who underwent palliative PTBD for more than 6 months is small due to the short survival time, which may introduce bias. Finally, this study did not fully address the associations between caregiver burden and clinical characteristics, such as chemotherapy status, mobility, nutritional support, and cancer recurrence; therefore, future research should undertake a more in-depth exploration of these factors. Despite these limitations, this study identified several key influencing factors of caregiver burden from both caregiver and patient perspectives. In future studies, interventions based on these identified influencing factors should be developed and validated.

Conclusion

Caregivers of cancer patients undergoing palliative PTBD experienced a considerable burden. Factors from both caregivers, such as the time spent on caring per day, levels of anxiety and depression, and family resilience, as well as factors related to the patients themselves, including age, gender, having more than one tube, and the tube maintenance institution, are influencing factors of caregiver burden. It is crucial for healthcare providers to develop interventions based on these influencing factors to help alleviate caregiver burden.

Supplementary Information

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Supplementary Material 1.

Authors' contributions

All authors contributed to the study conception and design. Material preparation, data collection and analysis were performed by Wei Zhu and Chaofeng Fan. The first draft of the manuscript was written by Wei Zhu and all authors commented on previous versions of the manuscript. All authors read and approved the final manuscript.

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Data availability

The datasets generated for this study are available on request to the corresponding author.

Declarations

Ethics approval and consent to participate

This study was performed in line with the principles of the Declaration of Helsinki. Approval was granted by the Ethics Committee of West China Hospital, Sichuan University (ID: 2024–100).
Informed consent was obtained from all individual participants included in the study.

Consent for publication

Not applicable.

Competing Interests

The authors declare no competing interests.

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