



# Informal caregiver burden and influencing factors in gynaecological oncology patients hospitalized for chemotherapy: a cross-sectional study

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## Abstract

**Objective:** To determine the level and influencing factors of informal caregiver burden in gynaecological oncology inpatients receiving chemotherapy.

**Methods:** This cross-sectional study enrolled gynaecological oncology patients and their informal caregivers between May 2018 and November 2018 and measured the caregivers' burden using the Caregiver Burden Inventory. The influencing factors were evaluated with univariate regression analysis and multivariate linear stepwise regression analysis.

**Results:** A total of 138 patients and their informal caregivers completed the questionnaire. The mean  $\pm$  SD total informal caregiver burden score was  $53.18 \pm 10.97$ . The highest mean  $\pm$  SD score was recorded in the dimension of time-dependent burden ( $14.28 \pm 2.74$ ), followed by developmental burden ( $13.65 \pm 2.15$ ), physical burden ( $10.52 \pm 2.07$ ), social burden ( $7.61 \pm 2.58$ ) and emotional burden ( $7.12 \pm 1.43$ ). Multivariate analysis showed that the informal caregiver's sex, relationship to the patient, daily duration of care, presence of chronic health problems and the duration of the patient's disease were factors influencing the level of caregiver burden.

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**Conclusions:** The informal caregivers of gynaecological cancer patients hospitalized for chemotherapy experience a moderate level of burden. Nursing measures should be considered to reduce informal caregiver burden and improve the quality of lives of both patients and their caregivers.

### Keywords

Gynaecological cancer patients, chemotherapy, informal caregiver burden, influencing factor

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### Introduction

The informal care delivered by those other than the hospital care team, for example a patient's family members, relatives and friends, is an essential complement to the professional care provided by clinicians. This is even more true for patients with a gynaecological malignancy. Their chemotherapy treatments might continue for months and require repeated hospitalizations. Non-employed or non-professional caregivers, also known as informal caregivers, play a vital role in caring for the patients on a daily basis.<sup>1</sup> Caregiver burden is a combination of the subjective negative feelings and the objective negative effects that are incurred by the care delivery during the care process, which in turn may have a potential impact on the patient's quality of life, treatment outcomes and rehabilitation.<sup>2</sup> Chemotherapy is the main treatment for gynaecological malignancies but it is associated with painful side-effects, which often require lengthy treatments and repeated hospitalizations, leading to an increased burden on the patients and their informal caregivers.<sup>3</sup> In China, gynaecological cancer patients typically undergo chemotherapies in inpatient settings and are discharged immediately after. They receive informal care in both the hospital and home. China's nationwide

public medical insurance system, which now covers over 99% of the Chinese population, pays up to 100% for chemotherapeutics on the List of Essential Medications issued by the National Health Authority.<sup>4</sup> Most of the medications are produced by Chinese pharmaceutical companies. Imported medications, on the other hand, are less covered, which are typically paid for by commercial medical insurance policies and/or by the patients themselves.<sup>5</sup> Informal caregivers usually have to commit most of their daily time to caring for the patient and discontinue their paid work.<sup>6</sup> Both parties may experience considerable physical, mental and financial stresses over the period of therapy.<sup>2,3,7</sup> By monitoring and mitigating the caregiver burden, it may be possible to ease the difficult healing process for both patient and caregiver; and potentially benefit the patient in terms of their chance of survival and quality of life.

Existing evidence on gynaecological oncology patients receiving chemotherapy tends to focus more on the quality of life of the patient rather than the burden upon their informal caregivers.<sup>8,9</sup> A literature search of the main databases including PubMed®, The Cochrane Library, Embase® and Ovid® using the terms of 'gynaecologic cancer', 'gynaecologic oncology', 'informal caregiver', 'chemotherapy', 'burden', 'influencing factors' and 'affecting

factors' for papers published between 2000 and 2020 returned no reports about the informal caregiver burden for this patient group. This is despite the fact that this patient group is known to need considerable care and support and whose quality of life and treatment outcomes may well be influenced by how well their informal care is delivered. This current study investigated the level of burden on informal caregivers of gynaecological cancer patients hospitalized for chemotherapy in order to explore the possible influencing factors. The current study aimed to provide evidence for developing nursing interventions and policy changes for physical and psychological improvements for both gynaecological patients and their informal caregivers.

## Patients and methods

### *Study population*

This cross-sectional study enrolled consecutive gynaecological cancer patients receiving chemotherapy in the Department of Gynaecology and Obstetrics, West China Second Hospital, Sichuan University, Chengdu, Sichuan Province, China between May 2018 and November 2018 and their informal caregivers. The inclusion criteria were as follows: (i) pathologically diagnosed with a gynaecological malignancy; (ii) currently receiving chemotherapy; (iii) had sufficient communication and writing abilities to complete the survey. The exclusion criteria were as follows: (i) diagnosis was not pathologically confirmed; (ii) communication or writing ability was insufficient to complete the survey. The inclusion criteria for the informal caregiver were as follows: (i) cared for the patient during the period that the patient was hospitalized for chemotherapy. For example, an informal caregiver that cared for an ovarian cancer patient for whole days during her

hospitalized chemotherapy; (ii) had cared for the patient for  $\geq 1$  month; (iii) was  $\geq 18$  years and  $\leq 70$  years of age; (iv) was a family member or a friend of the patient that provided care under no formal or informal employment; (v) was the patient's primary informal caregiver that provided the most care on a daily basis during the chemotherapy period; (vi) had sufficient communication ability to complete the survey. The exclusion criteria for the informal caregiver were as follows: (i) was hired and received remuneration for the care provided; (ii) was physically unable or unwilling to complete the survey because of inconvenient survey times or reluctance to participate; (iii) was not the primary caregiver and only provided care sporadically; (iv) was unable to complete the survey due to cognitive difficulties or illiteracy.

The study was approved by the Ethics Committee of West China Second Hospital, Sichuan University (no. 2018 [14]). Written informed consent was obtained from all of the patients and their informal caregivers.

### *Study instruments*

An informal caregiver sociodemographic questionnaire was developed to gather data including age, sex, educational level, ethnicity, marital status, home location, employment status, relationship to the patient, total duration of care, daily duration of care, presence of chronic health problems, willingness to care for the patient and whether they were having to take care of other family members.

A patient sociodemographic and clinical questionnaire was developed including age, ethnicity, education level, employment status, marital status, home location, monthly household income, type of payment for medical care, diagnosis, tumour staging, duration of disease, need of

surgery, prior surgery, need for radiotherapy and prior radiotherapy.

### Caregiver Burden Inventory

The Caregiver Burden Inventory (CBI) is a 24-item multidimensional questionnaire designed to quantify the burden on various aspects of a caregiver's life.<sup>10</sup> The measure includes five subscales to cover five dimensions of caregiver burden: time-dependence burden, which measures the time of caregiving (items 1–5); developmental burden, which reflects caregiver's feeling of being left behind and missing expectations and opportunities compared with his or her peers (items 6–10); physical burden, a subscale to measure the caregiver's feelings of fatigue and presence of chronic health problems (items 11–14); social burden, which quantifies perceived conflict of roles (items 15–19); and emotional burden, which measures the caregiver's negative feelings for the patient (items 20–24).<sup>10</sup> Each item is scored using a 5-point Likert scale from 0–4 points according to the severity of the burden. The total score of the CBI is 0–96. The higher the score is, the heavier the caregiver's burden is. The questionnaire is self-administered and takes approximately 10–15 min to complete. A score of 0–32 points is classified as a low burden, 33–64 as a moderate burden and 65–96 as a high burden.

The study used the Chinese version of the CBI that was translated previously.<sup>11</sup> The Cronbach's alpha coefficient of the Chinese CBI is 0.92, higher than the standard value 0.8, indicating good internal consistency.<sup>11</sup> The correlation coefficient between each item and the total score is 0.44 to 0.79, indicating that each item measures the caregiver's burden effectively.<sup>11</sup> The test-retest reliability is 0.93, which indicates good stability of the scale.<sup>11</sup>

### Data collection

Six investigators, each with an experience in gynaecological nursing for over 10 years, were trained to collect anonymous data on the patients and their informal caregivers.

### Statistical analyses

All statistical analyses were performed using SAS version 9.1 (SAS Institute Inc., Cary, NC, USA). Data are expressed as  $n$  (%) of participants or mean  $\pm$  SD. Inter-group comparisons were calculated using analysis of variance or Student's  $t$ -test. Influencing factors for informal caregiver burden were evaluated with multivariate linear stepwise regression analysis. All patient and informal caregiver factors collected were first evaluated with univariate regression analysis. The significant variables were then introduced into multivariate linear regression, with the total burden score as a dependent variable. A  $P$ -value  $< 0.05$  was considered statistically significant.

### Results

A total of 150 gynaecological cancer patients receiving chemotherapy were sent questionnaires for them and their informal caregivers; of these 138 valid questionnaires were returned (92.00%). Table 1 presents the sociodemographic data for the gynaecological cancer patients and their informal caregivers. The age of the gynaecological cancer patients ranged from 19 to 70 years (mean age, 58 years), including 58 patients aged  $\leq 44$  years (42.03%) and 80 aged  $> 44$  years (57.97%). Ovarian cancer was the most common diagnosis among the patients (68 of 138, 49.28%), followed by cervical cancer (45 of 138 patients, 32.61%), endometrial cancer (20 of 138 patients, 14.49%) and vulvar cancer or other gynaecologic malignancies (five of 138, 3.62%). Of all the gynaecological cancer patients, 38

**Table 1.** Sociodemographic characteristics of gynaecological oncology patients receiving chemotherapy and their informal caregivers ( $n = 138$ ).

Subject	Characteristic	<i>n</i>	%	
Informal caregiver	Sex	Male	86	62.32%
		Female	52	37.68%
	Age, years	≤44	53	38.41%
		>44	85	61.59%
	Ethnicity	Han	127	92.03%
		Minorities	11	7.97%
	Marital status	Married	128	92.75%
		Not married	10	7.25%
	Home location	Local	56	40.58%
		Not local	82	59.42%
	Employment	Employed	117	84.78%
		Unemployed	21	15.22%
	Education level	College or over	32	23.19%
		Lower than college	106	76.81%
	Monthly household income, Yuan RMB	<1000	17	12.32%
		1001–2000	43	31.16%
		2001–3000	53	38.41%
		3001–4000	11	7.97%
		>4000	14	10.14%
	Relationship to patient	Spouse	80	57.97%
		Parent/child	15	10.87%
		Sibling	16	11.59%
		Friend or others	27	19.57%
	Total duration of care, months	<3	41	29.71%
		3–6	45	32.61%
		7–12	36	26.09%
		>12	16	11.59%
	Daily duration of care, h	<6	11	7.97%
		6–12	75	54.35%
		>12	52	37.68%
Daily period of care time	Day	25	18.12%	
	Night	65	47.10%	
	Whole day	48	34.78%	
Had to care for other family members	Yes	108	78.26%	
	No	30	21.74%	
Chronic health problem	Yes	50	36.23%	
	No	88	63.77%	
Willing to care	Very willing	118	85.51%	
	Willing	18	13.04%	
	Unwilling	2	1.45%	
Patient	Diagnosis	Cervical cancer	45	32.61%
		Ovarian cancer	68	49.28%
		Endometrial cancer	20	14.49%
		Vulvar cancer or others	5	3.62%
	Age, years	≤ 44	58	42.03%
>44		80	57.97%	

(continued)

Table I. Continued.

Subject	Characteristic	n	%
Tumour staging	I	38	27.54%
	II	37	26.81%
	III	49	35.51%
	IV	14	10.14%
Duration of disease, months	<3	22	15.94%
	3–6	46	33.33%
	7–12	30	21.74%
	>12	40	28.99%
Need for surgery	Yes	103	74.64%
	No	35	25.36%
Have undergone surgery	Yes	95	68.84%
	No	43	31.16%
Need for radiotherapy	Yes	86	62.32%
	No	52	37.68%
Have undergone radiotherapy	Yes	42	30.43%
	No	96	69.57%

(27.54%) were stage I, 37 (26.81%) were stage II, 49 (35.51%) were stage III and 14 (10.14%) were stage IV. One-third of the patients (46 of 138, 33.33%) had had their disease for 3–6 months since diagnosis, 22 (15.94%) for <3 months, 30 (21.74%) for 7–12 months and 40 (28.99%) for >12 months. Surgery was needed in most cases (103 of 138, 74.64%) and 95 of 138 patients had already undergone one or more operations. More than half of the patients (86 of 138, 62.32%) needed radiotherapy and 42 of 138 patients (30.43%) had received it.

Of the 138 informal caregivers, 86 were men (62.32%) and 52 were women (37.68%), with a mean age of 52 years (range, 22–61 years). More than half of the informal caregivers (80 of 138, 57.97%) were the spouse of the patient, 15 were the patient's parents or children, 16 were siblings and 27 were friends or in another relationship with the patient. Most informal caregivers were married (128 of 138, 92.75%), not from the local city (82 of 138, 59.42%), held a job (117 of 138, 84.78%), had an education level

lower than college (106 of 138, 76.81%), had to care for other family members besides the patient (108 of 138, 78.26%) and did not have any chronic diseases (88 of 138, 63.77%). 127 informal caregivers were Han people in terms of ethnicity (92.03%) and 11 were minorities (7.97%). Most informal caregivers (107, 77.54%) made a monthly family income between 1000 and 4000 Yuan RMB (152–606 USD, exchange rate 6.6), 17 (12.32%) <1000 Yuan RMB and 14 (10.14%) >4000 Yuan RMB. Household incomes are further stratified in Table 1. In terms of duration of care, 16 of the 138 informal caregivers (11.59%) had cared for the patient for over 12 months, followed by 36 (26.09%) for 7–12 months, 45 (32.61%) for 3–6 months and 41 (29.71%) for <3 months. More than half of the informal caregivers (75 of 138, 54.35%) spent 6–12 h providing care every day, compared with 11 informal caregivers (7.97%) spending <6 h per day; and 52 of 138 informal caregivers (37.68%) cared for the patient for an extended period of >12 h per day. The majority of the informal caregivers



**Table 2.** Caregiver Burden Inventory scores for the informal caregivers of gynaecological cancer patients hospitalized for chemotherapy ( $n = 138$ ).

Burden	Dimension score	Item score <sup>a</sup>
Time-dependent	14.28 ± 2.74	2.89 ± 0.16
Developmental	13.65 ± 2.15	2.67 ± 0.23
Physical	10.52 ± 2.07	2.54 ± 0.66
Social	7.61 ± 2.58	2.06 ± 0.86
Emotional	7.12 ± 1.43	0.97 ± 0.65
Total	53.18 ± 10.97	

Data presented as mean ± SD.

<sup>a</sup>Mean score of the individual items within a dimension.

(118 of 138, 85.51%) indicated that they were very willing to take care of the patient, followed by 18 of 138 (13.04%) being willing and two of 138 (1.45%) said they were unwilling.

According to the CBI scores of the informal caregivers (Table 2), the mean ± SD total CBI score was 53.18 ± 10.97. The highest mean ± SD score was recorded in the dimension of time-dependent burden (14.28 ± 2.74), followed by developmental burden (13.65 ± 2.15), physical burden (10.52 ± 2.07), social burden (7.61 ± 2.58) and emotional burden (7.12 ± 1.43).

Table 3 presents the results of the univariate regression analysis of various factors in terms of CBI scoring. Eleven informal caregiver factors and four patient factors were found to have a significant effect on the informal caregiver burden. The informal caregiver factors were sex, age, marital status, employment, education level, total duration of care, daily duration of care, daily period of care time, have to care for other family members, presence of a chronic health problem and willingness to care. The patient factors were diagnosis, tumour staging, duration of disease and need for radiotherapy.

The significant factors from the univariate regression analysis were then introduced into a multivariate regression analysis with the total CBI score as a dependent variable,

which yielded five factors that significantly influence informal caregiver burden: informal caregiver sex, relationship to the patient, daily duration of care, having a chronic health problem and the patient's duration of disease (Table 4). The analysis used  $R^2$  as the power of a linear model to represent the percentage of the current variation of  $y$  to be explained by the independent variables in the current model. The variables were screened stepwise based on the inclusion and exclusion criteria.

## Discussion

As a mainstay treatment for gynaecological malignancies, chemotherapy can last for a long time and often requires repeated hospitalizations. The patients typically suffer both physically and psychologically.<sup>12</sup> Caring for a patient informally during chemotherapy can cause a variety of burdens upon the caregiver, who may be a family member, a relative or a friend of the patient.<sup>13</sup> This patient group and their caregivers seem to be less focused on in the international literature. The findings from the current study indicate a moderate level of burden experienced by the informal caregivers of gynaecological cancer patients hospitalized for chemotherapy and that factors such as the informal caregiver's sex, his or her relationship with the patient, the

**Table 3.** Univariate analysis of the Caregiver Burden Inventory (CBI) scores of gynaecological cancer patients and their informal caregivers during hospitalized chemotherapy ( $n = 138$ ).

Subject	Characteristic	<i>n</i>	%	CBI score	<i>t</i> / <i>F</i> value	<i>P</i> -value	
Informal caregiver	Sex	Male	86	62.32%	56.41 ± 6.22	<i>t</i> = 2.018	<i>P</i> = 0.018
		Female	52	37.68%	49.25 ± 4.25		
	Age, years	≤44	53	38.41%	44.65 ± 6.17	<i>F</i> = 1.741	<i>P</i> = 0.042
		> 44	85	61.59%	50.21 ± 3.29		
	Ethnicity	Han	127	92.03%	45.26 ± 6.17	<i>F</i> = 1.067	NS
		Minorities	11	7.97%	42.52 ± 2.75		
	Marital status	Married	128	92.75%	45.26 ± 6.17	<i>F</i> = 2.060	<i>P</i> = 0.032
		Not married	10	7.25%	36.52 ± 2.75		
	Home location	Local	56	40.58%	45.26 ± 6.17	<i>F</i> = 0.068	NS
		Not local	82	59.42%	44.14 ± 3.06		
	Employment	Employed	117	84.78%	45.26 ± 6.17	<i>F</i> = 2.335	<i>P</i> = 0.019
		Unemployed	21	15.22%	36.52 ± 2.75		
	Education level	College or over	32	23.19%	45.26 ± 6.17	<i>F</i> = 1.068	<i>P</i> = 0.018
		Lower than college	106	76.81%	39.52 ± 2.75		
	Monthly household income, Yuan RMB	< 1000	17	12.32%	43.56 ± 8.24	<i>F</i> = 10.571	NS
		1001–2000	43	31.16%	42.76 ± 6.32		
		2001–3000	53	38.41%	35.21 ± 6.18		
		3001–4000	11	7.97%	43.05 ± 6.02		
		> 4000	14	10.14%	48.61 ± 8.21		
	Relationship to patient	Spouse	80	57.97%	52.38 ± 5.54	<i>F</i> = 3.598	NS
		Parent/child	15	10.87%	41.74 ± 9.22		
		Sibling	16	11.59%	43.59 ± 5.49		
		Friend or others	27	19.57%	42.19 ± 6.53		
	Total duration of care, months	< 3	41	29.71%	45.06 ± 8.94	<i>F</i> = 9.258	<i>P</i> = 0.046
		3–6	45	32.61%	41.23 ± 6.34		
		7–12	36	26.09%	52.50 ± 7.87		
> 12		16	11.59%	53.74 ± 6.11			
Daily duration of care, h	< 6	11	7.97%	43.88 ± 7.39	<i>F</i> = 15.246	<i>P</i> < 0.001	
	6–12	75	54.35%	40.82 ± 4.71			
	> 12	52	37.68%	53.47 ± 7.28			
Daily period of care time	Day	25	18.12%	41.96 ± 7.39	<i>F</i> = 10.399	<i>P</i> < 0.001	
	Night	65	47.10%	45.21 ± 2.11			
	Whole day	48	34.78%	53.69 ± 6.95			
Have to care for other family members	Yes	108	78.26%	49.02 ± 7.15	<i>t</i> = 4.362	<i>P</i> = 0.038	
	No	30	21.74%	51.02 ± 6.15			
Chronic health problem	Yes	50	36.23%	56.58 ± 6.32	<i>t</i> = 4.362	<i>P</i> = 0.021	
	No	88	63.77%	42.58 ± 7.11			
Willingness to care	Very willing	118	85.51%	43.88 ± 7.39	<i>F</i> = 18.467	<i>P</i> < 0.001	
	Willing	18	13.04%	40.82 ± 4.71			
	Unwilling	2	1.45%	50.14 ± 3.25			
Patient	Diagnosis	Cervical cancer	45	32.61%	42.44 ± 6.55	<i>F</i> = 1.952	<i>P</i> = 0.001
		Ovarian cancer	68	49.28%	63.89 ± 6.15		
		Endometrial cancer	20	14.49%	52.95 ± 7.95		
		Vulvar cancer or others	5	3.62%	55.56 ± 11.28		
	Age, years	≤44	58	42.03%	46.15 ± 3.57	<i>F</i> = 0.581	NS
		> 44	80	57.97%	51.21 ± 2.22		
	Tumour staging	I	38	27.54%	42.44 ± 6.55	<i>F</i> = 1.952	<i>P</i> = 0.039
		II	37	26.81%	43.89 ± 6.15		
		III	49	35.51%	57.95 ± 7.95		
		IV	14	10.14%	55.56 ± 11.28		
< 3		22	15.94%	41.27 ± 9.76			

(continued)



**Table 3.** Continued.

Subject	Characteristic		n	%	CBI score	t/F value	P-value
	Duration of disease, months	3–6	46	33.33%	43.05 ± 7.44		
		7–12	30	21.74%	50.14 ± 6.25		
		> 12	40	28.99%	54.58 ± 6.05		
	Need for surgery	Yes	103	74.64%	53.58 ± 7.87	t = 0.081	NS
		No	35	25.36%	53.26 ± 6.42		
	Have undergone surgery	Yes	95	68.84%	53.84 ± 8.20	t = 1.504	NS
		No	43	31.16%	48.08 ± 3.25		
	Need for radiotherapy	Yes	86	62.32%	53.58 ± 7.87	t = 0.081	P = 0.047
		No	52	37.68%	43.26 ± 6.42		
	Have undergone radiotherapy	Yes	42	30.43%	53.84 ± 8.20	t = 1.504	NS
		No	96	69.57%	42.08 ± 5.71		

CBI data presented as mean ± SD.

NS, no significant between-group difference ( $P \geq 0.05$ ).

**Table 4.** Multivariate linear stepwise regression analysis of the factors influencing the informal caregiver burden ( $n = 138$ ).

Item	B value	SE value	$\beta$ value	t value	P-value
Constant	51.487	11.259	—	7.657	$P = 0.001$
Caregiver sex	1.456	1.519	0.147	1.067	$P = 0.026$
Relationship to the patient	2.156	0.359	0.269	5.149	$P = 0.005$
Daily duration of care	0.374	1.259	-0.108	-2.591	$P = 0.016$
Chronic health problems	2.146	2.574	-0.213	6.587	$P = 0.001$
Duration of disease	-0.531	0.251	-0.278	-1.258	$P = 0.001$

$R^2 = 0.534$ ;  $\Delta F = 11.237$ ;  $P < 0.001$ .

duration of care time every day, presence of chronic health problems in the informal caregiver and how long the patient has had the disease may play a role in determining the caregiver burden.

Given the prolonged treatments, repeated hospitalizations and the presence of a peripherally inserted central catheter (PICC), gynaecological cancer patients often experience problems such as fatigue, gastrointestinal reactions and hair loss. Their self-care abilities are considerably compromised, particularly when a PICC is in place.<sup>14</sup> Informal caregivers are often required to provide partial or total assistance with very basic daily living activities and body care, for long hours each day or even whole days. This could explain the

increased time-dependent burden in this current study, which is consistent with findings from a previous study.<sup>15</sup>

Gynaecological cancer patients often experience altered self-image as a result of their chemotherapy, including hair loss, poor emotional well-being and skin conditions. Some patients may be emotionally troubled by the loss of their female reproductive organs after surgery. In this current study, 68.84% of the patients had their diseased organs surgically removed and 30.43% underwent radiotherapy. The physical and endocrinological changes could impact on the patient's emotional well-being, which might cause them to refuse their husband's care and affections, leading to stress on both spouses.<sup>16</sup> It is worth

mentioning that many of the patients in the current study were cared for by their husbands. The loss of the uterus and ovarian function because of chemotherapy can cause some patients to experience an alteration in their self-identity, leading to a loss of their features as a woman and their appeal to their spouse.<sup>17</sup> This could sometimes result in them rejecting their husband's care, which in turn causes emotional stress on both spouses.<sup>17</sup> However, the emotional burden upon the informal caregivers in this current study was not particularly higher than the other dimensions. A possible explanation is that the husbands were confident to work through the difficult time with their wives and were able to keep a relatively calm state of mind in their marriage despite the heavy care burden. Such influences are certainly worth attention in future research, especially qualitative studies to describe the situation.

These current findings demonstrated that the men tended to experience a significantly greater burden as informal caregivers of gynaecological cancer patients on chemotherapy, which was consistent with a previous study.<sup>18</sup> According to a meta-analysis of the informal caregivers of oncology patients, the care tasks caused physical, social and emotional problems in addition to impacting on daily living and the informal caregiver's opinions were affected by their sex.<sup>19</sup> An analysis of the informal caregivers of cancer patients found that most of them were women, whose sex might help ease the care burden to some extent.<sup>20</sup> Continued guidance by healthcare professionals is also advised according to the results of this current study. It is reported that the families of cancer patients in China create WeChat support groups to provide information and emotional support; and psychological counsellors organize patients and their informal caregivers to join in

music therapies together, which proved helpful.<sup>21,22</sup>

In this current study, husbands caring for their wives reported the highest burden. In a spousal relationship, the husband as an informal caregiver has more responsibilities than a relative, friend or even other family members. In Chinese families, husbands and wives typically share multiple burdens such as family economy, child education, elderly parent support and other burdens. When the wife falls ill, the husband is faced with a sudden increase in burdens in addition to the new care tasks. He usually has to take over the wife's family duties while looking after her on a daily basis, sometimes even protecting her bodily privacy. The situation elevates his emotional, financial and time pressure burdens considerably. The current results were consistent with previous research findings.<sup>23</sup> Compared with other family members, a husband is typically more involved in close care delivery because they may experience less difficulties and obstacles in communication and other care-related activities thanks to their intimacy with the patient. In contrast, other informal caregivers such as parents and children could be hindered by their older or younger ages, pre-occupations at work or school or their less intimate relationship with the patient.

Nurses may consider offering interactive education sessions about the disease and treatments and encourage participation by both the patients and their caregivers, who may gain knowledge such as nutritional management and negative emotion handling during chemotherapy and share their experiences with each other. The process may help build patient-caregiver rapport and confidence and ease the burdens perceived by the caregivers. Isochronous health education for both patients and their family is useful for informing both the patient and their family in a timely

and accurate manner, providing a way to extend health education from hospital to home settings, which tends to improve the patient's confidence and quality of life.<sup>24</sup>

The burden was the highest among the informal caregivers providing care for more than 6 hours per day. The environmental conditions could be unpleasant in a hospital, particularly in a public hospital. Chemotherapy wards may be even less comfortable where usually 3–8 patients may share a room. The discomforts incurred by chemotherapy in one patient such as nausea, vomiting and pain may trigger anxiety, nervousness and worrying in the other patients on the ward. Procedures performed on one of the patients and conversations between the healthcare workers during the night may disturb the sleep of the others. Physically and psychologically stressful care delivery in such a strange environment for an extended period tends to cause the informal caregivers to experience various discomforts such as irritability, loss of appetite, gastrointestinal discomfort and deterioration of sleep quality. The current results were partially consistent with previous research results.<sup>25</sup> Informal care provided by multiple caregivers in shorter durations is recommended. Additionally, ward nurses, outpatient clinics and community care can also be helpful temporary resources.

According to the current results, informal caregivers that had chronic health conditions were exposed to greater burden. The poorer health, the greater the caregiver's physical burden was, which was consistent with the findings of previous studies.<sup>26,27</sup> In this current study, 36.23% of the informal caregivers had chronic health conditions. They tend to experience greater care burdens compared with their healthy counterparts. The informal caregiver's health problems should be considered when deciding who should care for the patient and properly addressed in the care process.

More robust replacement caregivers should be arranged if possible.

The physical and psychological status of gynaecological cancer patients are generally less favourable during the cycles of chemotherapy. As the duration of chemotherapy increases, it is more likely that the patient will develop disease and functional deterioration, with increased adverse reactions and drug side-effects. For example, lower extremity venous return disorder and lymphoedema, which cause difficulty in walking, abdominal pain, sleep disturbance and aggravate the patient's pain.<sup>28</sup> The severity and condition of the patient's symptoms are closely linked with her informal caregiver's levels of depression and anxiety.<sup>29</sup> As a result, the patient's level of awareness of the disease, communication and duration of care needed may all bear impact on how much burden the caregiver experiences as the disease course continues.<sup>30</sup> It is suggested that informal caregivers engaging in longer terms of care provision may need, in addition to the necessary knowledge and skills, even better communication with the patient and other family members to be adequately encouraged, supported and rested to prevent them from falling into a vicious cycle of emotional insufficiency and incapacity to care.<sup>31</sup>

In conclusion, informal caregivers of gynaecological cancer patients hospitalized for chemotherapy experience a moderate level of burden. The sex of the informal caregiver, their relationship with the patient, daily duration of care, having chronic health problems and the patient's duration of disease are major factors influencing caregiver burden. Increased physical, mental and social attention and support for the informal caregivers are advisable. Nursing outreach services such as home visits and phone call follow-up should be considered for chemotherapy wards and clinics. Participatory health education involving the informal caregivers

may be explored for better humanitarian nursing support during chemotherapy to ease their lasting tension and fatigue, lower their burden and eventually improve the quality of lives of both patients and their informal caregivers.


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