

# Burden on caregivers of ventilator-dependent patients

## A cross-sectional study

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### Abstract

Caring for prolonged mechanical ventilation (PMV) patients imposes heavy psychological, physical, social, and financial burdens on caregivers. Currently, studies regarding the burden on caregivers of PMV patients are scant; therefore, the present study investigated the burden on caregivers of PMV patients.

This cross-sectional study was approved by the Institutional Review Board of Zuoying Armed Forces General Hospital. A survey was conducted among the caregivers of PMV patients who were admitted to a chronic respiratory care ward (RCW) or were receiving home care from June to December 2010. The survey included basic demographic information of PMV patients and their caregivers and the Burden Assessment Scale scores for 4 domains comprising a total of 21 questions (physical burden,  $n=5$ ; psychological burden,  $n=6$ ; social burden,  $n=6$ ; financial burden,  $n=4$ ). Statistical analyses were conducted using the  $t$  test, 1-way analysis of variance with the *Scheffé* post hoc test, and the chi-square test, and  $P < .05$  was considered statistically significant.

A total of 160 caregivers (age, 50–53 years) were recruited ( $n=80$  each in the home care and RCW groups), and most of these caregivers were married women. Due to insufficient sleep, physical exhaustion, back pain, and caregiving, home caregivers had significantly higher physical burden levels than RCW caregivers ( $P < .01$ ).

Home caregivers experienced higher physical burden levels than RCW caregivers. Therefore, clinical and professional support must be provided to home caregivers of PMV patients.

**Abbreviations:** BAS = Burden Assessment Scale, ICU = intensive care unit, IDS = integrated delivery system, PACs = post-acute care units, PMV = prolonged mechanical ventilation, RCW = respiratory care ward, TNHI = Taiwan's National Health Insurance Administration.

**Keywords:** burden, Burden Assessment Scale, caregivers, home care, prolonged mechanical ventilation, respiratory care ward

## 1. Introduction

Substantial use of mechanical ventilation has saved many lives in the last century; however, the number of patients receiving prolonged ventilator support with complex healthcare requirements has increased. Patients requiring prolonged mechanical

ventilation (PMV) in an intensive care unit (ICU) has accounted for 4% to 13% of overall admissions.<sup>[1,2]</sup> Therefore, healthcare systems in developed countries have established a step-down approach, such as post-acute care units (PACs), to care for PMV patients and satisfy their requirements.<sup>[3]</sup> Patient transfer from ICU to PACs has successfully reduced the number of PMV patients from 62% to 18%, consequently increasing the number of patients in PACs from 22% to 46% and those in long-term respiratory care centers from 2% to 24%.<sup>[1]</sup>

In 1998, Taiwan's National Health Insurance Administration (TNHI), Ministry of Health and Welfare, established a ventilator-dependent integrated delivery system (IDS) and developed a policy to provide support and care to PMV patients. On the basis of the duration of ventilator use, an integrated management system was used that divided medical care into 4 phases, including ICU, respiratory care center, chronic respiratory care ward (RCW), and home care. After achieving stable conditions, such patients are gradually transferred from ICU to home care.<sup>[4]</sup> According to the TNHI, PMV is defined as the continuous use of mechanical ventilation for more than 21 days. Approximately 30,000 patients were categorized as PMV patients in 2014, and the medical costs of these patients accounted for 4.76% of Taiwan's total healthcare expenditure. With a rapid increase in the number of PMV patients, financial burden has become a concern for the healthcare system. These expenses cause psychological, physical, social, and financial stresses in such patients as well as their caregivers.<sup>[5,6]</sup> Most PMV patients and families in Taiwan prefer to reside in institutional care centers,

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and home care is not commonly accepted.<sup>[7]</sup> Currently, only 8% of PMV patients have been transferred to home care after hospital discharge.

Studies have revealed that increased psychological stress due to the fear of handling emergency situations is the primary reason of patients and caregivers for refusing home care.<sup>[5,8–11]</sup> Home and RCW caregivers of PMV patients have different concerns. Previous studies have revealed that caregivers of patients receiving institutional care are concerned about patients' health status and future medical care requirements.<sup>[10,12–14]</sup> Caregivers have decreased social contact and experience guilt about leaving their patients alone in RCWs and managing their own family demands. In addition, the cost of patients' stay in RCWs is high, which increases the financial burden. Therefore, the present study investigated the burden on home and RCW caregivers of PMV patients.

## 2. Materials and methods

The present study was conducted between June and December 2010 and was reviewed and approved by the Institutional Review Board of Zuoying Armed Forces General Hospital in Taiwan, and informed consent was obtained from all caregivers. The primary caregivers were who made surrogate decision, who paid for the medical expenses, and who were the family members caring for the patient in the most of time. Paid assistants and hired foreign caregivers were excluded from participating the survey.

The structured questionnaire included demographic information of PMV patients and their caregivers and the Burden Assessment Scale (BAS) scores. The BAS comprises 4 domains with a total of 21 questions (physical burden,  $n=5$ ; psychological burden,  $n=6$ ; social burden,  $n=6$ ; financial burden,  $n=4$ ). A 5-point Likert scale was used to score the BAS domains, and higher scores represented higher levels of caregiver burden. Sampling adequacy was measured using the Kaiser–Meyer–Olkin coefficient of 0.828 because a value of 0.8–1 indicates adequate

sampling. The content validity was examined using Cronbach's  $\alpha$  coefficient of 0.941 and 0.923 for reliability analysis and the survey, respectively.

Data was analyzed using SPSS (version 23.0, IBM Inc., NY). Descriptive data are presented as means, standard deviations (SDs), and percentages. Statistical analyses included the independent sample  $t$  test, 1-way analysis of variance with the *Scheffé* post hoc test, and the chi-square test, and  $P < .05$  was considered statistically significant.

## 3. Results

The screened caregivers were administered 302 questionnaires, and 160 caregivers ( $n=80$  each in the home care and RCW groups) of PMV patients participated in the survey with an overall response rate of 53% (Fig. 1).

Table 1 presents the demographic characteristics of PMV patients and their caregivers. Patients who required PMV were mainly elderly people, with an average age of 63–74 years (home care group vs RCW group:  $63.75 \pm 22.78$  vs  $74.36 \pm 16.95$  y) and an average ventilator use duration of 22 to 33 months. The percentage of tracheotomy surgery patients was significantly higher in the home care group than in the RCW group (91.6% vs 76.6%). The number of conscious patients was significantly higher in the home care group than in the RCW group (67.5% vs 41.1%).

Table 2 illustrates that home caregivers were significantly younger, were predominantly women, and a higher percentage of them were patients' spouses. Home caregivers appeared to receive more social welfare support than RCW caregivers; however, no statistical significance was achieved ( $P = .053$ ). The financial sources of home caregivers were highly abundant, whereas a higher percentage of self-funding was observed among RCW caregivers ( $P = .009$ ).

The BAS results (Table 3) demonstrated that among the 4 domains, the physical burden scores were significantly higher in

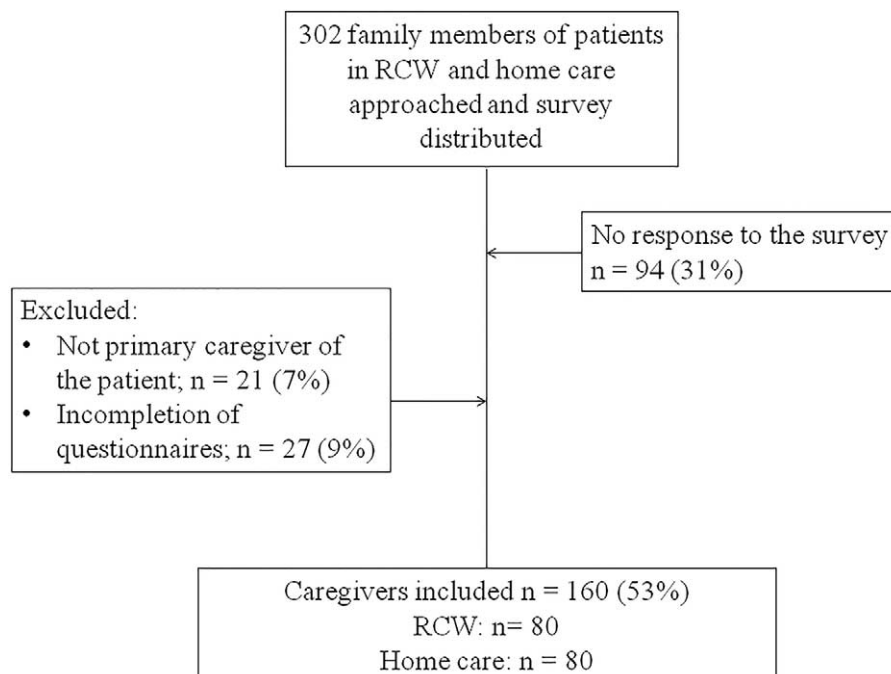


Figure 1. Flow diagram of caregiver enrollment.

**Table 1**  
Demographic characteristic of PMV patients.

Characteristics	RCW (N=80)	HC (N=80)	P
Age, years	74.36 ± 16.95	63.75 ± 16.95	.001*
Duration of ventilator use, months	22.43 ± 26.63	32.04 ± 33.43	.046*
Men	38 (47.5%)	49 (61.3%)	.081
Employment prior to illness			.987
Military/public/education-based	9 (11.3%)	9 (11.3%)	
Agricultural/industrial/business	21 (26.3%)	24 (27.5%)	
Self-employed	7 (8.8%)	8 (10%)	
None	43 (53.8%)	41 (51.3%)	
Being a primary financial source	22 (27.5%)	30 (37.5%)	.177
Educational level			.099
Illiterate	20 (25%)	17 (21.3%)	
Elementary school	41 (51.3%)	40 (50%)	
Secondary school	11 (13.8%)	16 (20%)	
Higher education	8 (10%)	7 (8.8%)	
Religion			.733
None	15 (8.8%)	15 (18.8%)	
Buddhism/Taoism	59 (73.8%)	55 (68.8%)	
Christian/catholic	5 (6.3%)	9 (11.3%)	
Others	1 (1.3%)	1 (1.3%)	
Consciousness status			.001*
Conscious	30 (37.5%)	55 (68.8%)	
Unconscious	50 (62.5%)	25 (31.2%)	
Artificial airway type			.010*
Endotracheal intubation	19 (23.8%)	7 (8.8%)	
Tracheotomy	61 (76.2%)	73 (91.2%)	

HC = home care, RCW = respiratory care ward.

\*Significant different between groups by T-test.

home caregivers than RCW caregivers (12.10 ± 3.65 vs 10.50 ± 4.25). The factors attributing physical burden included insufficient sleep, physical exhaustion, and back pain (all  $P < .05$ ). Home caregivers had a significantly poorer health status than RCW caregivers.

Although no significant differences were observed in the total scores for the psychological, social, and financial burden domains, post hoc analysis revealed that home caregivers had reduced social contact with friends and families ( $P = .009$ ). RCW caregivers reported increased medical bills ( $P = .041$ ) and increased expenses from hiring a caretaker ( $P = .001$ ), resulting in a frugal lifestyle ( $P < .028$ ). Because of these additional expenses, RCW caregivers might experience more difficulties than home caregivers.

#### 4. Discussion

The present results demonstrated that home caregivers experience a higher physical burden, whereas RCW caregivers have a significantly higher economic burden. Caregivers of PMV patients experience a heavy psychological burden regardless of whether these patients receive institutional care or home care.

##### 4.1. Characteristics of caregivers of PMV patients

Our study showed that caregivers were mostly married women (home vs RCW caregivers: 71.5% vs 57.5%) and patients' children, thus demonstrating the influence of traditional Chinese culture that has general concepts, such as "Men work outside the home, whereas women do domestic work."<sup>[15]</sup> However, studies have shown similar results. For example, Douglas and Daly<sup>[16]</sup> observed that caregivers of long-term ventilator-dependent

**Table 2**  
Demographic characteristics of caregivers.

Characteristics	RCW (N=80)	HC (N=80)	P
Age, years	53.59 ± 9.69	50.59 ± 14.92	.556
Men	34 (42.5%)	22 (27.5%)	.047*
Marital status			.113
Single	9 (11.3%)	19 (23.8%)	
Married	67 (83.8%)	58 (72.5%)	
Divorced/widowed	4 (5%)	3 (3.8%)	
Educational level			.072
Illiterate	5 (6.3%)	4 (5%)	
Elementary school	16 (20%)	27 (33.8%)	
Secondary school	26 (32.5%)	29 (36.3%)	
Higher education	33 (41.3%)	20 (25%)	
Religion			.237
None	12 (15%)	18 (22.5%)	
Buddhism/Taoism	64 (80%)	53 (66.3%)	
Christian/catholic	3 (3.8%)	6 (7.5%)	
Others	1 (1.3%)	3 (3.8%)	
Relationship with patient			.011*
Son/daughter	4 (5%)	14 (17.5%)	
Spouse	17 (21.3%)	26 (32.5%)	
Children	54 (67.5%)	36 (45%)	
Other relations	5 (6.3%)	4 (5%)	
Under social welfare	12 (15%)	22 (27.5%)	.053
Annual household income			.282
Below 7500	11 (13.8%)	14 (17.5%)	
7600–12,000	20 (25%)	13 (16.3%)	
12,100–18,000	19 (23.8%)	29 (36.3%)	
18,100–25,000	14 (17.5%)	9 (11.3%)	
Above 25,100	16 (20%)	15 (18.8%)	
Financial sources			.006*
Self	48 (60%)	24 (30%)	
Spouse	14 (17.5%)	24 (30%)	
Parents	5 (6.3%)	9 (11.3%)	
Children	10 (12.5%)	17 (21.3%)	
Others	3 (3.8%)	6 (7.5%)	
Current health status			.009*
Very poor	3 (3.8%)	15 (18.8%)	
Poor	17 (21.3%)	23 (28.8%)	
Normal	45 (56.3%)	32 (40.0%)	
Healthy	16 (18.8%)	10 (12.5%)	
Health status after caregiving			.041*
Very poor	9 (11.3%)	22 (27.5%)	
Poor	31 (38.8%)	29 (36.3%)	
Normal	37 (46.3%)	29 (36.3%)	
Healthy	3 (3.8%)	0	
Jobless due to patient's illness	15 (18.8%)	24 (30%)	.097

HC = home care, RCW = respiratory care ward.

\*Significant different between groups by T-test.

patients were mainly middle-aged women. Their tasks not only included caring for their family members but also performing household chores and managing the burden resulting from patients' ailments, mental status, and social life. These women were experienced higher stress and were at a higher risk of mental disorders, such as depression.<sup>[6,17]</sup> Therefore, physical, mental, spiritual, and social pressures and difficulties are among the most important concerns for female caregivers. In addition, the present results revealed that caregivers believed that their health status was extremely poor. Douglas and Daly<sup>[16]</sup> moreover reported that the health status upon caregivers of PMV patients encountered a higher degree of health problems.<sup>[16]</sup> Furthermore, as the physical and mental health statuses of PMV patients decline, the stress and burden on caregivers increase, and they tend to develop depressive symptoms. Health-care providers

**Table 3**  
**BAS scores (mean ± SD).**

Domains/items	RCW (N = 80)	HC (N = 80)	P
Physiological burden	10.50 ± 4.25	12.10 ± 3.65	.012*
Lack of sleep or rest	2.75 ± 1.15	3.29 ± 0.99	.002*
Constant tiredness/restlessness	2.75 ± 1.14	3.18 ± 1.01	.014*
Torso pain	2.63 ± 1.25	3.09 ± 1.08	.014*
Worsening of physiological status or illness	2.38 ± 1.16	2.55 ± 1.11	.332
Psychological burden	15.15 ± 4.31	15.34 ± 4.15	.780
Loss of appetite	2.31 ± 1.05	2.50 ± 0.91	.230
Feeling pressured and tempered	2.69 ± 1.10	3.00 ± 1.09	.074
Frustration and helplessness	2.93 ± 1.16	2.95 ± 1.05	.887
Feeling of care insufficiency	3.51 ± 1.19	3.38 ± 1.08	.446
Fear of patient's disease deterioration	3.71 ± 1.03	3.51 ± 1.05	.228
Social burden	13.80 ± 5.00	14.64 ± 3.91	.240
Neglecting the care of other family members	2.65 ± 1.18	2.50 ± 0.99	.386
Unable to handle household chores	2.66 ± 1.11	2.84 ± 0.90	.277
Time constraints	2.84 ± 1.11	3.10 ± 1.01	.122
Change in personal plans	2.89 ± 1.14	2.96 ± 1.10	.675
Less interaction with friends and families	2.76 ± 1.09	3.24 ± 1.16	.009*
Financial burden	13.16 ± 4.42	11.80 ± 4.69	.061
Decreased income due to joblessness	2.44 ± 1.42	2.74 ± 1.40	.181
High medical bills leading to frugal lifestyle	3.48 ± 1.32	3.01 ± 1.31	.028*
Increased expenses due to caretaker fees	3.75 ± 1.35	2.98 ± 1.53	.001*
Financial difficulties due to medical bills	3.50 ± 1.34	3.08 ± 1.26	.041*

BAS = Burden Assessment Scale, HC=home care, RCW=respiratory care ward.

\*Significant different between groups by T-test.

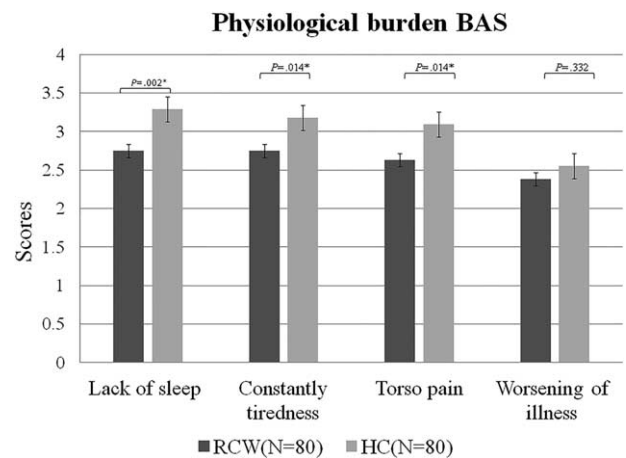
should be more alert to recognizing the symptoms of depression in this caregiver population and should refer caregivers to mental health professionals for further evaluation and treatment.

The present results revealed that caregivers believed that their health status is extremely poor. Hickman and Douglas<sup>[18]</sup> found that the health status of PMV patients gradually worsens with increased risks. As the physical and mental statuses of PMV patients decline, the stress and burden on caregivers increase, and they tend to develop highly depressive symptoms.

Filial piety is an important feature of the traditional Chinese society, where family ethics are highly valued, and members are assigned duties according to their identities in the family. These duties have even become social behavior norms. Occasionally, children make sacrifices to foster family interest, resolve conflicts, and achieve family tranquility and harmony. Furthermore, to avoid judgment and blame from the society, family members generally abide by family ethics and social norms. Nevertheless, this behavior can put them at a higher risk of cognitive dissonance.<sup>[15,16]</sup> From a financial resource perspective, caregivers' spouses typically experience more burden than caregivers themselves. Caregivers provide patient care, whereas their spouses handle household and living expenses, thus attributing higher financial burden.<sup>[19]</sup>

#### 4.2. Different effects of burden on caregivers

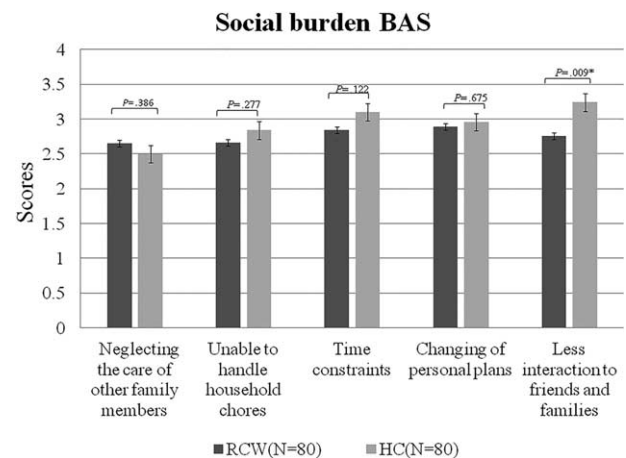
Our study observed noticeable differences in the physical burden levels of the 2 caregiver groups. Home caregivers had higher physical burden levels than RCW caregivers due to insufficient sleep and rest, physical exhaustion, and back pain symptoms (Fig. 2).



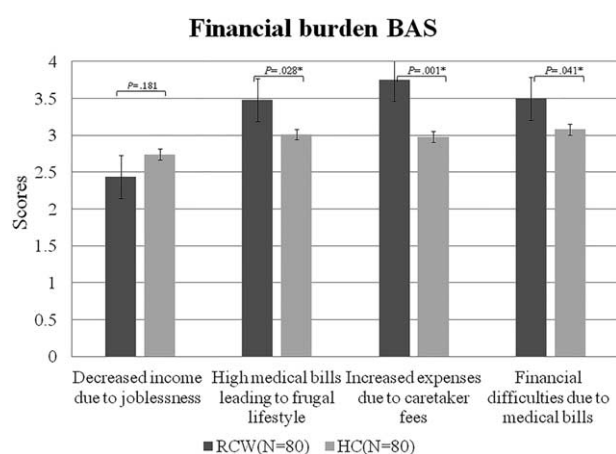
**Figure 2.** Comparison of physical burden scores. \* $P < .05$  by T-test between groups.

Providing home care to patients typically changes the lifestyle of caregivers. Home caregivers of PVM patients can experience sleep insufficiency and have worsened health status and increased physical burdens. Evan reported that home caregivers of ventilator-dependent patients experienced physical, emotional, and time-dependent burdens. The participants experienced time constraints in caring for their loved ones and “restriction to almost all parts of life: career, finances, hobbies, and leisure, and many hardly left the house at all.”<sup>[20]</sup> Similarly, in the present study, caregivers reported higher scores for the following items: lack of sleep, torso pain, and less interaction with friends. The TNHI and the Ministry of Health and Welfare in Taiwan are aware of the physical burdens to caregivers; therefore, respite service programs have developed to alleviate physical and social burdens of home caregivers. However, the caregivers of those participants were yet lack of support and in need of further social resources.

The results of domain analysis showed that home caregivers had higher social burden levels than RCW caregivers. Many home caregivers believed that they socialized less with friends and families than before (Fig. 3). This finding is consistent with Wu and Tseng<sup>[21]</sup> study in 2009, which showed that the life of home caregivers of ventilator-dependent patients became highly



**Figure 3.** Comparison of social burden scores. \*Significant different between groups by T-test.



**Figure 4.** Comparison of financial burden scores. \*Significant different between groups by T-test.

restricted because increased attention was required. Therefore, caregivers may not be able to leave the patient even for a moment, resulting in decreased outside-world interaction.

Furthermore, our study demonstrated that RCW caregivers experienced significantly higher financial burden levels than home caregivers. Economic obligations are considered as a common burden on many caregivers, and patients residing in institutional care wards are the main reason for increased expenses (Fig. 4). Hung estimated that the average lifetime cost for a PMV patient USD 60,000, of which USD 32,000 was paid by the TNHI and 28,000 by the patient of family.<sup>[22]</sup> According to various institutional care standards, although RCW patients' expenses are partly covered by TNHI, caregivers are required to afford approximately USD 7000–10,000 for additional expenses per year, including RCW expenses, care supply, and nutritional supplement fees. Such expenses increase caregivers' stress. In 2002, Lee showed that many caregivers of RCW patients believed: "Even if the fees charged by hospitals are reasonable, expenditure of this kind will make it even harder for families to maintain themselves." Therefore, the longer the ventilator use, the heavier the financial burden on families.<sup>[23,24]</sup> Patients and their family must be informed of financial burden during the clinical decision-making process. Furthermore, the disease management program through integrative, multidisciplinary team management may facilitate the family to cope financial stress, by involving social workers, case managers, and financial advisor to address family concerns and finding social network supports.<sup>[18]</sup>

van Beusekom performed a systematic review and observed that 20% to 50% informal caregivers of ICU survivors developed post-trauma stress disorder, depression, or anxiety at 6 months after ICU discharge.<sup>[25]</sup> Evans reported that caregivers are unaware of patient's disease and disease progression.<sup>[20]</sup> The BAS results of our study revealed that the 2 caregiver groups had high psychological burden scores, and the item, fear of patient's disease deterioration, had the highest score. Although all caregivers in our study had been caring for their loved ones since an average of 2 to 3 years, they experienced the same burdens as those reported in previous studies, which may indicate insufficient caregiver training and education by healthcare providers. A previous study demonstrated a significant relationship between caregivers' disease awareness and decreased burden on caregivers.<sup>[25]</sup> Educational and psychological programs should provide information on several aspects, including disease

information, care organization, practical advice, skills training for equipment handling, decision-making, funding resources, emotional repercussions on caregivers, and self-care advice.<sup>[21,26]</sup> In addition, prolonged support to caregivers is recommended. Additionally, with the advance of information technology, mobile computing is becoming an important tool healthcare, in which enhances and promotes communication. Chiang et al found that providing educational program by tab to provide psychological support, educational information needed, and connection to the supportive groups reduced anxiety in family members.<sup>[27]</sup> Davidson et al suggested psychological screening of family members for symptoms of depression, anxiety, acute stress disorder, and posttraumatic stress disorder.<sup>[28]</sup>

A few methodological limitations should be considered while deriving implications of our findings. First, this cross-sectional study was conducted in 1 center; therefore, 1-time assessments in caregivers of PMV patients can be influenced by variable assessment conditions on a particular day. Second, sample representativeness may be questionable because only 69% of caregivers responded to the questionnaires.

## 5. Conclusions

Home caregivers have higher physical burden levels than RCW caregivers. However, RCW caregivers experience higher financial burden levels than home caregivers, leading to financial difficulties and frugal lifestyle. The present results reflect the current situations faced by caregivers. Therefore, we highly recommend that clinical and professional healthcare personnel should provide caregivers with social support, financial aid, and healthcare to alleviate their stress and reduce their burden.

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