Stress on caregivers providing prolonged mechanical ventilation patient care in different facilities: A cross-sectional study

Yeong-Ruey Chu1*, Chin-Jung Liu2,3*, Chia-Chen Chu2, Pei-Tseng Kung4†, Wen-Yu Chou5, Wen-Chen Tsai5‡*

1 Department of Public Health, China Medical University, Taichung, Taiwan, 2 Department of Respiratory Therapy, China Medical University Hospital, Taichung, Taiwan, 3 School of Nursing, China Medical University, Taichung, Taiwan, 4 Department of Healthcare Administration, Asia University, Taichung, Taiwan, 5 Department of Health Services Administration, China Medical University, Taichung, Taiwan

Purpose
Taiwan has implemented an integrated prospective payment program (IPP) for prolonged mechanical ventilation (PMV) patients that consists of four stages of care: intensive care unit (ICU), respiratory care center (RCC), respiratory care ward (RCW), and respiratory home care (RHC). We aimed to investigate the life impact on family caregivers of PMV patients opting for a payment program and compared different care units.

Method
A total of 610 questionnaires were recalled. Statistical analyses were conducted by using the chi-square test and multivariate logistic regression model.

Results
The results indicated no associations between caregivers’ stress levels and opting for a payment program. Participants in the non-IPP group spent less time with friends and family owing to caregiver responsibilities. The results of the family domain show that the RHC group (OR = 2.54) had worsened family relationships compared with the ICU group; however, there was less psychological stress in the RCC (OR = 0.54) and RCW (OR = 0.16) groups than in the ICU group. In the social domain, RHC interviewees experienced reduced friend and family interactivity (OR = 2.18) and community or religious activities (OR = 2.06) than the ICU group. The RCW group felt that leisure and work time had less effect (OR = 0.37 and 0.41) than the ICU group. Furthermore, RCW interviewees (OR = 0.43) were less influenced by the reduced family income than the ICU group in the economic domain.
Conclusions
RHC family caregivers had the highest level of stress, whereas family caregivers in the RCW group had the lowest level of stress.

Introduction
Prolonged mechanical ventilation (PMV) is defined as the operation of a mechanical ventilation support system for more than 6 hours per day and exceeding 21 days [1, 2]. The PMV incidence rates per 100 ICU admissions in Europe and the US were found to be 5%-11% [3–6]. Taiwan had a PMV rate per 100 mechanical ventilation patients of 20% [7], while China had a PMV rate of 36% [8], and some PMV patients were found to occupy intensive care unit (ICU) beds. To increase the emergency department turnover rate, control medical expenses, and increase the weaning rate of mechanical ventilation, weaning centers (also called subacute or post-acute care) have been established to rapidly liberate patients from the need for mechanical ventilators in the United States [9, 10], Europe [4, 11], and Taiwan [12–14].

The Taiwan National Health Insurance provides a comprehensive payment system for integrated prospective payment plans for PMV patients called integrated prospective payment program (IPP) who are at least 17 years old. This system has integrated payments with managed care systems since July 2000 [2]. This IPP plan covers four types of care and different payments, including ICU for critical care, respiratory care centers (RCCs) for step-down subacute units, respiratory care ward (RCW) for long-term care facilities, and respiratory home care (RHC) for PMV patients [2]. The regulation of IPP are fee-for-service ICU care (within 21 d), per-diem RCC (for up to 42 d), per capitation RCW, and per-month home ventilation service. The ICU, RCC, and RCW belong to the institutions, and 24 hours medical staff are available. The patients who use ventilators at home have nurses and respiratory therapists visit twice a month and physician visit once two months.

The intervention of the IPP has increased the turnover rate of ICU beds and reduced the length of hospital stay. However, PMV patients in RCC, RCW, and RHC have seen a significant increase in the length of required care [13–15]. Studies that as general home care patients are more familiar with the environment at home, they feel more comfortable, amenable, and experience a better than in-house care group [16]. However, it was also found that most PMV patients were elderly patients [17, 18] with poor life function independence [19] and had a greater care burden which directly affected their family caregivers [20–24].

Caregivers’ fear of caring for PMV patients can cause stress on the physical health, mind, and soul of both the patients and caregivers [25]. Moreover, it can impose financial burdens on families. Studies show low willingness in the main caregivers of PMV patients because of the high pressure that the job puts on them [16, 20, 26]. However, there is a shortage of studies exploring whether the burden of main family caregivers with patients at different unit has been affected by the IPP two decades ago. This study aimed to compare the associations between caregivers’ stress levels and opting for a payment program, and compared with the impaction of life on caregivers of PMV patients in the different units.

Materials and methods
Questionnaire development
We invited 10 PMV subject care experts from each type of institution in northern, central, and southern Taiwan to constitute a panel of experts. The primary family members of the three
PMV patients and three nursing staff members from the same RCW formed a focus group to identify the structure and content of the questionnaire items. The content of the questionnaire included (1) the characteristics of respondents, (2) the characteristics of PMV patients, (3) the effect of care for PMV patients on their families, society, and family finances (S1 File); and (4) relevant information on mechanical ventilation.

The questionnaires have three domains (family, social, and economic). They measured aspects related to their lives by a Likert scale (from strongly agree to strongly disagree) to compare the impact of the IPP and different units of primary caregivers of PMV patients on the stress of life. Then we invited five experts to assess the validity of the questionnaire content following the completion of its design. The average content validity index (CVI) was 0.96 (0.73 to 1.00). The reliability of the questionnaire was measured using the Kuder-Richardson Formula 20 (KR-20). After the questionnaire was tested, the KR-20 coefficient of this study was found to be 0.78.

**Power of sample size**

This was a cross-sectional observational study. According to Mohamad Adam Bujang et al.’s recommendation for observational large-sample studies using logistic regression, the minimum sample size needs to be at least 500 [27]. A sufficient total of 601 valid samples were collected in this study.

**Participants**

The participants included in this study were at least 20 years of age and served as the main family caregivers of PMV patients from northern, central, and southern Taiwan. According to our definition of the stages of PMV patients, the acute ICU stage was the time in ICU and/or less than 7 days in RCC after transfer from ICU; the subacute stage was ≥30 days of stay in RCC; the chronic stage was ≥30 days of RCW stay; and finally, the RHC was ≥30 days of using a mechanical ventilator at home. The participants were divided into two groups (IPP and none-IPP group) according to whether they had joined IPP.

**Participant consent**

Because patients are mostly unconscious, interviewers are required to assist in collecting patients’ clinical information, so the research required medical staff, case managers, or respiratory therapists to recruit those who understood the situation of the subjects to agree to do the interview and explain the parameters to the respondents according to the interview instructions (S2 File). This study was approved by the institutional review board of the China Medical University Hospital (IRB No. CMUH102-REC3-105).

**Statistical analysis**

Chi-square tests were used to compare the characteristics of patients with PMV in terms of subject characteristics, mechanical ventilation status, and the difference between the impact on the main caregivers of patients at different stages. Finally, we combined “strongly agree,” “agree” and “no objection” into one group and “disagree” and “strongly disagree” into another group, and used the logistic regression model to compare the differences in stress levels experienced by the main family caregivers for ICU, RCC, RCW, and RHC patients. Statistical significance was set at \( p < 0.05 \), and SAS (version 9.4, SAS Institute Inc., Cary, NC, USA) was used for the analysis.
Results

Respondent and patient characteristics
As comprehensive analyses datasets were generated by a previous study [28], including 687 eligible respondents from 64 institutions (6 medical centers, 11 regional hospitals, 23 district hospitals, 15 nursing homes, and 9 home care centers) (S3 File). The study was conducted from November 1, 2013, to April 15, 2014. A total of 601 questionnaires were completed (effective questionnaire response rate 87%) and 50.75% were women, with an average age of 51.88 years. A majority of the responses were provided by children of PMV parents (54.74%). The monthly expense paid by the family for the IPP group was significantly lower than that for the non-IPP group (USD 745 vs. USD 912 respectively) (Table 1). The average age of the PMV patients was 70.76 years. Only 38.77% of patients were in a state of alert consciousness, with 34.78% with near-terminal illnesses. A total of 89.35% of the patients had daily mechanical ventilation of 19–24 hours (Table 2).

Impact of caring for PMV patients on families
Significantly more caregivers in the non-IPP group ($p = 0.039$), compared with the IPP group, reported reduced time with friends and family. In addition, there were no significant statistical differences in other factors (Table 3).

Impact of socioeconomic conditions, caregiver occupation, underlying diseases of the patients on caregiver stress levels and family relationships
We used family income and education level to represent the socioeconomic conditions of caregivers. We then compared the family income and education level of the caregivers of PMV patients at four stages with the psychological pressure and family relationship using Spearman’s rank correlation. In addition, we used the Chi-square test to analyze the patient’s underlying disease, psychological pressure on the caregiver, and family relationships. The results showed that there was no significant difference in the family income of caregivers between psychological stress and family relationships. However, we found that the higher the education level, the lower the adverse effect on the relationship between family members; moreover, this difference was statistically significant ($p < 0.05$) (see Table 4). There was no significant correlation between the underlying disease of PMV patients and the psychological stress on caregivers and family relationships (Table 5).

Regarding the impact on the family caregivers’ life among the ICU, RCC, RCW and RHC groups, results showed that respondents from the RHC group showed more agreement to the item, "Taking care of the patient worsens the relationship between family members” than interviewees in the ICU group (OR = 2.54 (95%CI 1.60–4.05), $p < 0.001$); however, respondents from the RCW group showed less agreement to the item, "I experienced physical stress because caring for the patient” than those in the ICU group (OR = 0.61 (95%CI 0.38–1.00), $p = 0.05$). For the item, “I feel psychologically stressed from caring for the patient,” respondents from the RCC (OR = 0.54 (95%CI 0.29–0.99), $p = 0.048$) and RCW (OR = 0.46 (95%CI 0.25–0.85), $p = 0.012$) groups showed less agreement than those from the ICU group (Fig 1) (S4 File).

In the social domain, for items such as "I feel that my time for my friends and family has reduced because of caring for the patient” and “I feel that the time for community or religious activities has reduced because of caring for the patient,” caregivers in the RHC group showed more agreement than those in the ICU group (OR = 2.18 (95%CI 1.21–3.92), $p = 0.01$ and OR = 2.06 (95%CI 1.15–3.68), $p = 0.014$, respectively). For items such as “I feel that leisure time has decreased because of caring for the patient,” the RCC and RCW groups were in less
agreement than those in the ICU group (RCC, $OR = 0.47$ (95%CI 0.26–0.86), $p = 0.014$ and RCW, $OR = 0.37$ (95%CI 0.21–0.67, $p<0.001$). For the item, “My work is affected because of caring for the patient.” the RCW group was in less agreement than the ICU group (OR = 0.41 (95%CI 0.24–0.69), $p<0.001$) (Fig 2) (S4 File).

In the economic domain, the ICU group (OR = 0.43 (95%CI 0.26–0.72), $p = 0.001$) (Fig 3) (S4 File) had a greater level of agreement with the item “Reduced family income due to inability to work owing to caregiving responsibilities,” than the RCW group.

### Table 1. Demographic characteristics of respondents with and without IPP.

| Variables                        | Total N = 601 | Non-IPP: N = 207 | IPP: N = 394 | p value |
|----------------------------------|---------------|-----------------|--------------|---------|
| Gender                           |               |                 |              |         |
| Male                             | 296 (49.25)   | 99 (47.83)      | 197 (50.00)  | 0.674   |
| Female                           | 305 (50.75)   | 108 (52.17)     | 197 (50.00)  |         |
| Age in years                     |               |                 |              |         |
| Mean age (SD)                    | 51.88 (11.84) | 53.30 (11.59)   | 51.13 (11.92)| 0.032*  |
| Educational level                |               |                 |              | 0.504   |
| None                             | 13 (2.16)     | 7 (3.38)        | 6 (1.52)     |         |
| ≤Grade 9                         | 161 (26.79)   | 53 (25.60)      | 108 (27.41)  |         |
| High school to college           | 403 (67.05)   | 139 (67.15)     | 264 (67.01)  |         |
| Graduate school                  | 24 (3.99)     | 8 (3.86)        | 16 (4.06)    |         |
| Married                          |               |                 |              | 0.636   |
| Yes                              | 480 (80.00)   | 170 (82.13)     | 310 (78.88)  |         |
| Never                            | 90 (15.00)    | 28 (13.53)      | 62 (15.78)   |         |
| Been married                     | 30 (5.00)     | 9 (4.35)        | 21 (5.34)    |         |
| Monthly salary in USD            |               |                 |              | 0.194   |
| <1000                            | 154 (25.71)   | 45 (21.84)      | 109 (27.74)  |         |
| 1000–2000                        | 235 (39.23)   | 94 (45.63)      | 141 (35.88)  |         |
| 2000–3000                        | 125 (20.87)   | 42 (20.39)      | 83 (21.12)   |         |
| 3000–4000                        | 51 (8.51)     | 15 (7.28)       | 36 (9.16)    |         |
| ≥4000                            | 34 (5.68)     | 10 (4.85)       | 24 (6.11)    |         |
| Religion                         |               |                 |              | 0.746   |
| Yes                              | 502 (83.53)   | 171 (82.61)     | 331 (84.01)  |         |
| No                               | 99 (16.47)    | 36 (17.39)      | 63 (15.99)   |         |
| Relationship with PMV patient    |               |                 |              | 0.423   |
| Parents                          | 41 (6.82)     | 8 (3.86)        | 33 (8.38)    |         |
| Couple                           | 111 (18.47)   | 42 (20.29)      | 69 (17.51)   |         |
| Children                         | 329 (54.74)   | 115 (55.56)     | 214 (54.31)  |         |
| Children-in-law                  | 59 (9.82)     | 21 (10.14)      | 38 (9.64)    |         |
| Brothers and sisters             | 27 (4.49)     | 10 (4.83)       | 17 (4.31)    |         |
| Grandchildren                    | 17 (2.83)     | 7 (3.38)        | 10 (2.54)    |         |
| Other                            | 17 (2.83)     | 4 (1.93)        | 13 (3.30)    |         |
| Can someone take turns taking care of the patient with you? | | | | 0.809|
| No                               | 194 (32.28)   | 65 (31.40)      | 129 (32.74)  |         |
| Yes                              | 407 (67.72)   | 142 (68.60)     | 265 (67.26)  |         |
| Average monthly expense (USD)    | 801.69 (902.27) | 912.61 (601.97) | 745.3553 (1017.66) | 0.014 |

IPP: integrated prospective payment program.
One US dollar (USD) was 30 New Taiwan dollars (NTD) on Sep. 2013.

# t-test.

https://doi.org/10.1371/journal.pone.0268884.t001
Discussion

The PMV patients and respondents had an average age of 70.76 and 51.88 years respectively. Of the main caregivers, 54.74% were children, and 80% of them were married. In the IPP group, the monthly expenses spent on patients were significantly lower than those of the non-IPP group. The caregivers of home-based patients experienced higher stress levels than caregivers of patients in another stage. The caregivers of ICU patients also experienced high stress levels, but only second to those taking care of home-based patients. Furthermore, it was found that caregivers of RCW patients had significantly lower stress levels than the family caregivers of patients in other situations.

This study demonstrated that the stress levels experienced by caregivers of home-based PMV patients (RHC) were 1.21–2.54 times that of their counterparts who care for ICU patients. According to the results, caregivers of home-based PMV patients had poorer sleep quality [29], higher risks of depression, and poorer health conditions [30, 31]. We also found that although caregivers of home-based patients had higher stress levels than those of RCW patients [29], the difference was not significant. As demonstrated in our study, the stress level of the caregivers of home-based patients was the highest, followed by that of caregivers of ICU,
Table 3. Comparison of the impact of IPP for PMV patients on the life of caregivers.

| Variables | All | | Non-IPP | | IPP | | p value |
|-----------|-----|----|--------|----|--------|----|--------|
| N         | %   | N  | %      | N  | %      |    |        |
| Total     | 601 | 100| 207    | 34.44| 394    | 65.56|        |

### [Family domain]

Taking care of the patient worsens the relationship between family members. 0.199

|                     | All |        | Non-IPP |        | IPP |        |
|---------------------|-----|--------|---------|--------|-----|--------|
| strongly disagree   | 112 | 18.64  | 37      | 17.87  | 75  | 19.04  |
| disagree            | 227 | 37.77  | 81      | 39.13  | 146 | 37.06  |
| no objection        | 91  | 15.14  | 37      | 17.87  | 54  | 13.71  |
| agree               | 133 | 22.13  | 36      | 17.39  | 97  | 24.62  |
| strongly agree      | 38  | 6.32   | 16      | 7.73   | 22  | 5.58   |

I feel that family life is affected because of caring for the patient 0.195

|                     | All |        | Non-IPP |        | IPP |        |
|---------------------|-----|--------|---------|--------|-----|--------|
| strongly disagree   | 47  | 7.82   | 14      | 6.76   | 33  | 8.38   |
| disagree            | 121 | 20.13  | 53      | 25.60  | 68  | 17.26  |
| no objection        | 76  | 12.65  | 25      | 12.08  | 51  | 12.94  |
| agree               | 285 | 47.42  | 91      | 43.96  | 194 | 49.24  |
| strongly agree      | 72  | 11.98  | 24      | 11.59  | 48  | 12.18  |

I experience physical stress because of caring for the patient 0.051

|                     | All |        | Non-IPP |        | IPP |        |
|---------------------|-----|--------|---------|--------|-----|--------|
| strongly disagree   | 46  | 7.65   | 12      | 5.80   | 34  | 8.63   |
| disagree            | 132 | 21.96  | 59      | 28.50  | 73  | 18.53  |
| no objection        | 98  | 16.31  | 28      | 13.53  | 70  | 17.77  |
| agree               | 242 | 40.27  | 79      | 38.16  | 163 | 41.37  |
| strongly agree      | 83  | 13.81  | 29      | 14.01  | 54  | 13.71  |

I feel psychologically stressed from caring for the patient 0.651

|                     | All |        | Non-IPP |        | IPP |        |
|---------------------|-----|--------|---------|--------|-----|--------|
| strongly disagree   | 27  | 4.49   | 9       | 4.35   | 18  | 4.57   |
| disagree            | 83  | 13.81  | 32      | 15.46  | 51  | 12.94  |
| no objection        | 56  | 9.32   | 22      | 10.63  | 34  | 8.63   |
| agree               | 306 | 50.92  | 97      | 46.86  | 209 | 53.05  |
| strongly agree      | 129 | 21.46  | 47      | 22.71  | 82  | 20.81  |

### [Social domain]

I feel that my time for my friends and family has reduced because of caring for the patient 0.039

|                     | All |        | Non-IPP |        | IPP |        |
|---------------------|-----|--------|---------|--------|-----|--------|
| strongly disagree   | 36  | 5.99   | 12      | 5.80   | 24  | 6.09   |
| disagree            | 126 | 20.97  | 56      | 27.05  | 70  | 17.77  |
| no objection        | 121 | 20.13  | 31      | 14.98  | 90  | 22.84  |
| agree               | 247 | 41.10  | 82      | 39.61  | 165 | 41.88  |
| strongly agree      | 71  | 11.81  | 26      | 12.56  | 45  | 11.42  |

I feel that the time for community or religious activities has reduced because of caring for the patient 0.170

|                     | All |        | Non-IPP |        | IPP |        |
|---------------------|-----|--------|---------|--------|-----|--------|
| strongly disagree   | 37  | 6.16   | 13      | 6.28   | 24  | 6.09   |
| disagree            | 124 | 20.63  | 53      | 25.60  | 71  | 18.02  |
| no objection        | 144 | 23.96  | 50      | 24.15  | 94  | 23.86  |
| agree               | 225 | 37.44  | 66      | 31.88  | 159 | 40.36  |
| strongly agree      | 71  | 11.81  | 25      | 12.08  | 46  | 11.68  |

I feel that leisure time has decreased because of caring for the patient 0.125

|                     | All |        | Non-IPP |        | IPP |        |
|---------------------|-----|--------|---------|--------|-----|--------|
| strongly disagree   | 28  | 4.66   | 9       | 4.35   | 19  | 4.82   |
| disagree            | 88  | 14.64  | 39      | 18.84  | 49  | 12.44  |
| no objection        | 95  | 15.81  | 38      | 18.36  | 57  | 14.47  |
| agree               | 286 | 47.59  | 88      | 42.51  | 198 | 50.25  |
| strongly agree      | 104 | 17.30  | 33      | 15.94  | 71  | 18.02  |

My work is affected because of caring for the patient 0.392

(Continued)
RCC, and RCW patients. Therefore, apart from continued attention paid to the stress of the main caregivers of home-based PMV patients [20, 22, 29, 30, 32, 33], we cannot ignore the stress experienced by caregivers of ICU patients.

The results showed that caregivers of ICU and RHC patients had higher stress levels than those of RCC and RCW patients. This might be caused by uncertainties in emergency medical treatments performed to save the lives of ICU patients [34–37] and the pressure to make life-making decisions on behalf of the patients [38]. These caregivers may have a higher risk of developing depression [39] because their stress levels increase with the severity of the patients’ condition [40]. Although RCC and RCW patients were mechanical ventilator users, they had already experienced the uncertainty of the acute phase. At this point, their family members

Table 3. (Continued)

| Variables                                      | All | Non-IPP | IPP |
|-----------------------------------------------|-----|---------|-----|
|                                               | N   | %       | N   | %       | N   | %       | p value |
| strongly disagree                             | 34  | 5.66    | 13  | 6.28    | 21  | 5.33    |
| disagree                                      | 113 | 18.8    | 47  | 22.71   | 66  | 16.75   |
| no objection                                  | 118 | 19.63   | 41  | 19.81   | 77  | 19.54   |
| agree                                         | 213 | 35.44   | 66  | 31.88   | 147 | 37.31   |
| strongly agree                                | 123 | 20.47   | 40  | 19.32   | 83  | 21.07   |

It is difficult to find proper social support or assistance to take care of the patient

| strongly disagree                             | 37  | 6.16    | 9   | 4.35    | 28  | 7.11    |
| disagree                                      | 149 | 24.79   | 63  | 30.43   | 86  | 21.83   |
| no objection                                  | 132 | 21.96   | 40  | 19.32   | 92  | 23.35   |
| agree                                         | 206 | 34.28   | 65  | 31.40   | 141 | 35.79   |
| strongly agree                                | 77  | 12.81   | 30  | 14.49   | 47  | 11.93   |

Reduction family income due to inability to work owing to caregiving responsibilities

| strongly disagree                             | 42  | 6.99    | 11  | 5.31    | 31  | 7.87    |
| disagree                                      | 110 | 18.30   | 46  | 22.22   | 64  | 16.24   |
| no objection                                  | 113 | 18.80   | 40  | 19.32   | 73  | 18.53   |
| agree                                         | 216 | 35.94   | 72  | 34.78   | 144 | 36.55   |
| strongly agree                                | 120 | 19.97   | 38  | 18.36   | 82  | 20.81   |

I am under financial pressure because of the cost of caring for the patient

| strongly disagree                             | 21  | 3.49    | 7   | 3.38    | 14  | 3.55    |
| disagree                                      | 62  | 10.32   | 28  | 13.53   | 34  | 8.63    |
| no objection                                  | 105 | 17.47   | 33  | 15.94   | 72  | 18.27   |
| agree                                         | 260 | 43.26   | 88  | 42.51   | 172 | 43.65   |
| strongly agree                                | 153 | 25.46   | 51  | 24.64   | 102 | 25.89   |

IPP: integrated prospective payment program; PMV: prolonged mechanical ventilation.

https://doi.org/10.1371/journal.pone.0268884.t003

Table 4. The socioeconomic conditions and occupation of caregiver’s impact on stress level and family relationship.

| Variables                          | Family income of caregiver | Education of caregiver |
|------------------------------------|---------------------------|------------------------|
|                                    | correlation coefficient   | p-value\(^1\)          | correlation coefficient | p-value\(^1\)          |
| Family relationship                | -0.017                    | 0.677                  | -0.166                  | <0.001                  |
| Psychologically stressed           | 0.008                     | 0.850                  | -0.080                  | 0.050                   |

\(^1\)Spearman’s rank correlation test.

https://doi.org/10.1371/journal.pone.0268884.t004
Table 5. Association of underlying diseases of the patients with stress level and family relationship.

| Underline disease | Chronic pulmonary disease | Central neuropathy | Catastrophic illness | Others | P-value¹ |
|-------------------|---------------------------|--------------------|----------------------|--------|----------|
|                   | n            | %        | n          | %         | N   | %         | n  | %         |
| Psychologically stressed |          |          |            |          |     |           |    |           |
| strongly disagree | 4           | 3.05     | 9          | 4.86      | 9   | 4.31      | 5  | 6.58      |
| disagree          | 17          | 12.98    | 22         | 11.89     | 37  | 17.70     | 7  | 9.21      |
| no objection      | 12          | 9.16     | 12         | 6.49      | 22  | 10.53     | 10 | 13.16     |
| agree             | 67          | 51.15    | 99         | 53.51     | 104 | 49.76     | 36 | 47.37     |
| strongly agree    | 31          | 23.66    | 43         | 23.24     | 37  | 17.70     | 18 | 23.68     |
| Total             | 131         | 21.80    | 185        | 30.78     | 209 | 34.78     | 76 | 12.65     |
| Family relationship |          |          |            |          |     |           |    |           |
| strongly disagree | 19          | 14.50    | 38         | 20.54     | 38  | 18.18     | 17 | 22.37     |
| disagree          | 51          | 38.93    | 64         | 34.59     | 89  | 42.58     | 23 | 30.26     |
| no objection      | 19          | 14.50    | 22         | 11.89     | 39  | 18.66     | 11 | 14.47     |
| agree             | 32          | 24.43    | 50         | 27.03     | 34  | 16.27     | 17 | 22.37     |
| strongly agree    | 10          | 7.63     | 11         | 5.95      | 9   | 4.31      | 8  | 10.53     |
| Total             | 131         | 21.80    | 185        | 30.78     | 209 | 34.78     | 76 | 12.65     |

¹Chi-square test.

https://doi.org/10.1371/journal.pone.0268884.t005

Fig 1. Odds of agreement in the life impact of the caregivers of PMV patients at various stages at family domain.

https://doi.org/10.1371/journal.pone.0268884.g001
could support each other in caring for patients using only shared knowledge for methods of care. As the caregivers no longer needed to attend to patients 24 hours a day, the stress they experienced was significantly lower than that experienced by caregivers of home-based patients [29].

**[Social Domains]**

| Items | OR (95% CI) | P       |
|-------|-------------|---------|
| I feel that my time for my friends and family has reduced because of caring for the patient. | ICU: 1 | RCC: 0.63(0.38-1.02) | 0.062 |
|       |            | RCW: 0.75(0.45-1.23) | 0.253 |
|       |            | RHC: 2.18(1.21-3.92) | 0.010 |
| I feel that the time for community or religious activities has reduced because of caring for the patient. | ICU: 1 | RCC: 0.68(0.41-1.12) | 0.131 |
|       |            | RCW: 0.72(0.44-1.19) | 0.206 |
|       |            | RHC: 2.06(1.15-3.68) | 0.015 |
| I feel less leisure time has decreased because of caring for the patient. | ICU: 1 | RCC: 0.47(0.26-0.86) | 0.014 |
|       |            | RCW: 0.37(0.21-0.67) | <0.001 |
|       |            | RHC: 1.40(0.69-2.84) | 0.359 |
| My work is affected because of caring for the patient. | ICU: 1 | RCC: 0.61(0.35-1.05) | 0.076 |
|       |            | RCW: 0.41(0.24-0.69) | <0.001 |
|       |            | RHC: 1.21(0.67-2.11) | 0.525 |
| It is difficult to find proper social support or assistance to take care of the patient. | ICU: 1 | RCC: 0.69(0.43-1.13) | 0.140 |
|       |            | RCW: 0.70(0.47-1.23) | 0.265 |
|       |            | RHC: 1.28(0.77-2.15) | 0.342 |

**[Economic Domains]**

| Items | OR (95% CI) | P       |
|-------|-------------|---------|
| Reduced family income due to inability to work owing to caregiving responsibilities. | ICU: 1 | RCC: 0.70(0.41-1.18) | 0.182 |
|       |            | RCW: 0.43(0.258-0.72) | 0.001 |
|       |            | RHC: 1.78(0.964-3.27) | 0.066 |
| I am under financial pressure because of the cost of caring for the patient. | ICU: 1 | RCC: 0.90(0.466-1.72) | 0.739 |
|       |            | RCW: 0.64(0.345-1.20) | 0.162 |
|       |            | RHC: 1.78(0.838-3.79) | 0.133 |

**Fig 2. Odds of agreement in the life impact of the caregivers of PMV patients at various stages at social domain.**

https://doi.org/10.1371/journal.pone.0268884.g002

**Fig 3. Odds of agreement in the life impact of the caregivers of PMV patients at various stages at economic domain.**

https://doi.org/10.1371/journal.pone.0268884.g003
Since the main caregivers of home-based PMV patients needed to take care of the patients, they had to give up part of their time with family, their comforts of life, and their opportunities to communicate and build relationships with friends and relatives [41]. Notwithstanding, patients with PMV have a poor prognosis [42]. The considerable expense and physical fatigue can aggravate psychological and physical stress experienced by family members, as well as increase socioeconomic burdens over time [21–23, 31, 34]. As a result, most caregivers of PMV patients choose to work with medical institutions instead of taking total care of patients themselves [29, 43]. The caregivers of RCW patients had significantly lower stress levels than those of patients in other situations, indicating that medical institutions were of great help in relieving caregivers’ stress. Therefore, PMV care centers in medical institutions can help family caregivers get plenty of rest and reduce the stress they experience [34].

The strengths of our study conducted a large number of participants from 64 institutions. However, some limitations were considered. First, the impact of the socioeconomic condition of participants on stress level on family is not clear. Second, we used income and education to represent the socioeconomic condition which might not be a complete evaluation.

Conclusions
Family caregivers of RHC patients had the highest level of stress, followed by their counterparts who care for ICU patients; further, the stress levels of caregivers are not associated with IPP. Higher the education level, the lower the adverse effect on the relationship between family members. Future studies to investigate the relationship between socioeconomic condition and stress level is suggested.

Supporting information
S1 File. Question about the impact of taking care of prolonged mechanical ventilation patients on life (English and Chinese version).
(DOCX)

S2 File. Interviewees manual (English and Chinese version).
(DOCX)

S3 File. 64 Interviewee’s institutions information.
(DOCX)

S4 File. The impact on the family caregivers’ life between the ICU, RCC, RCW and RHC groups.
(DOCX)

Acknowledgments
We are grateful to these 64 participants of hospitals/institutions for providing administrative support. We are also grateful to Health Data Science Center, China Medical University Hospital for providing administrative and technical support.

Author Contributions
Conceptualization: Pei-Tseng Kung, Wen-Chen Tsai.

Data curation: Chin-Jung Liu, Chia-Chen Chu, Pei-Tseng Kung, Wen-Chen Tsai.

Formal analysis: Yeong-Ruey Chu, Chin-Jung Liu, Chia-Chen Chu, Pei-Tseng Kung, Wen-Yu Chou, Wen-Chen Tsai.
Funding acquisition: Pei-Tseng Kung, Wen-Chen Tsai.
Investigation: Yeong-Ruey Chu, Chin-Jung Liu, Chia-Chen Chu, Pei-Tseng Kung, Wen-Yu Chou, Wen-Chen Tsai.
Methodology: Yeong-Ruey Chu, Chia-Chen Chu, Pei-Tseng Kung, Wen-Yu Chou, Wen-Chen Tsai.
Project administration: Yeong-Ruey Chu, Chia-Chen Chu, Pei-Tseng Kung, Wen-Chen Tsai.
Resources: Yeong-Ruey Chu, Chia-Chen Chu, Pei-Tseng Kung, Wen-Yu Chou, Wen-Chen Tsai.
Software: Pei-Tseng Kung, Wen-Chen Tsai.
Supervision: Pei-Tseng Kung, Wen-Chen Tsai.
Validation: Yeong-Ruey Chu, Chin-Jung Liu, Pei-Tseng Kung, Wen-Yu Chou, Wen-Chen Tsai.
Visualization: Pei-Tseng Kung, Wen-Chen Tsai.
Writing – original draft: Yeong-Ruey Chu, Chin-Jung Liu, Pei-Tseng Kung, Wen-Chen Tsai.
Writing – review & editing: Yeong-Ruey Chu, Chin-Jung Liu, Pei-Tseng Kung, Wen-Chen Tsai.

References
1. MacIntyre NR, Epstein SK, Carson S, Scheinhorn D, Christopher K, Muldoon S. Management of patients requiring prolonged mechanical ventilation: report of a NAMDRD consensus conference. Chest. 2005; 128(6):3937–54. https://doi.org/10.1378/chest.128.6.3937 PMID: 16354866
2. National Health Insurance Administration Ministry of Health and Welfare. Integrated delivery system with a prospective payment program for ventilator-dependent patients. 2000 [cited 2017 Jan. 21]. Available from: http://www.nhi.gov.tw/webdata/webdata.aspx?menu=8&menu_id=498&webdata_id=3048
3. Kahn JM, Le T, Angus DC, Cox CE, Hough CL, White DB, et al. The epidemiology of chronic critical illness in the United States*. Crit Care Med. 2015; 43(2):282–7. https://doi.org/10.1097/CCM.0000000000000710 PMID: 25377018
4. Lone NI, Walsh TS. Prolonged mechanical ventilation in critically ill patients: epidemiology, outcomes and modelling the potential cost consequences of establishing a regional weaning unit. Crit Care. 2011; 15(2):R102. https://doi.org/10.1186/cc1017 PMID: 21439086
5. Loss SH, de Oliveira RP, Maccari JG, Savii A, Boniatti MM, Hetzel MP, et al. The reality of patients requiring prolonged mechanical ventilation: a multicenter study. Revista Brasileira de terapia intensiva. 2015; 27(1):26–35. https://doi.org/10.5935/0103-507X.20150006 PMID: 25909910
6. Rose L, Fowler RA, Fan E, Fraser I, Leasa D, Mawdsley C, et al. Prolonged mechanical ventilation in Canadian intensive care units: a national survey. J Crit Care. 2015; 30(1):25–31. https://doi.org/10.1016/j.jcrc.2014.07.023 PMID: 25201807
7. Wu SC, Wu TN, Hung YN. Set up and apply the health information database and parameters for patients with ventilator dependent. Department of Health, Executive Yuan; 2012. p. 73.
8. Li J, Zhan QY, Wang C. Survey of Prolonged Mechanical Ventilation in Intensive Care Units in Mainland China. Respir Care. 2016; 61(9):1224–31. https://doi.org/10.4187/respcare.04295 PMID: 27460102
9. Scheinhorn DJ, Hassenpflug MS, Votto JJ, Chao DC, Epstein SK, Doig GS, et al. Post-ICU mechanical ventilation at 23 long-term care hospitals: a multicenter outcomes study. Chest. 2007; 131(1):85–93. https://doi.org/10.1378/chest.06-1081 PMID: 17218560
10. Scheinhorn DJ, Hassenpflug MS, Votto JJ, Chao DC, Epstein SK, Doig GS, et al. Ventilator-dependent survivors of catastrophic illness transferred to 23 long-term care hospitals for weaning from prolonged mechanical ventilation. Chest. 2007; 131(1):76–84. https://doi.org/10.1378/chest.06-1079 PMID: 17218559
11. Polverino E, Nava S, Ferrer M, Ceriana P, Cmin E, Spada E, et al. Patients’ characterization, hospital course and clinical outcomes in five Italian respiratory intensive care units. Intensive care medicine. 2010; 36(1):137–42. https://doi.org/10.1007/s00134-009-1656-2 PMID: 19784622
12. Lin MS, Yan YH, Wang JD, Lu HM, Chen L, Hung MC, et al. Improved survival for an integrated system of reduced intensive respiratory care for patients requiring prolonged mechanical ventilation. Respiratory care. 2013; 58(3):517–24. https://doi.org/10.4187/respcare.01530 PMID: 22906762

13. Liu CJ, Chu CC, Chen W, Cheng WE, Shih CM, Tsai YS, et al. Impact of Taiwan’s integrated prospective payment program on prolonged mechanical ventilation: a 6-year nationwide study. Respiratory care. 2013; 58(4):676–82. https://doi.org/10.4187/respcare.01242 PMID: 23050858

14. Liu CJ, Kung PT, Chu CC, Chou WY, Wang YH, Tsai WC. Propensity score-matching analyses on the effectiveness of integrated prospective payment program for patients with prolonged mechanical ventilation. Health policy (Amsterdam, Netherlands). 2018; 122(9):970–6. https://doi.org/10.1016/j.healthpol.2018.07.009 PMID: 30097352

15. Wu S-C, Hung Y-N. Set up and apply the health information database and parameters for patients with ventilator dependence. Institute of Health and Welfare Policy, National Yang-Ming University: Ministry of Health and Welfare; 2013.

16. Leff B, Burton L, Mader S, Naughton B, Burl J, Clark R, et al. Satisfaction with hospital at home care. Journal of the American geriatrics society. 2006; 54(9):1355–63. https://doi.org/10.1111/j.1532-5415.2006.00855.x PMID: 16970642

17. Yeh L. Characteristics of institutionalized ventilator dependent client in tainan area. Thoracic medicine. 2001; 16(4):236–43.

18. Douglas SL, Daly BJ, Brennan PF, Gordon NH, Uthis PJC. Hospital readmission among long-term ventilator patients. Chest. 2001; 120(4):1278–86. https://doi.org/10.1378/chest.120.4.1278 PMID: 11591572

19. Chiang L-L, Wu C-P, Wang L-Y, Wu Y-T. Functional status and quality of life in ventilator-dependent patients. Formosan journal of physical therapy. 2004; 29(1):40–7.

20. Wu Y-H, Tseng Y-H. The lived experience of family caregivers caring for ventilator-dependent patients at home. The journal of long-term care. 2009; 13(2):169–89.

21. Cox CE, Carson SS. Medical and economic implications of prolonged mechanical ventilation and expedited post-acute care. Seminars in respiratory and critical care medicine. 2012; 33(4):357–61. https://doi.org/10.1055/s-0032-1321985 PMID: 22875381

22. Sevick MA, Bradham DD. Economic value of caregiver effort in maintaining long-term ventilator-assisted individuals at home. Heart lung. 1997; 26(2):148–57. https://doi.org/10.1016/s0147-9563(97)90075-3 PMID: 9090520

23. Cox CE, Carson SS, Govert JA, Chelluri L, Sanders GD. An economic evaluation of prolonged mechanical ventilation. Crit Care Med. 2007; 35(8):1918–27. https://doi.org/10.1097/01.CCM.0000275391.35834.10 PMID: 17581479

24. Seear M, Kapur A, Wensley D, Morrison K, Behroozi A. The quality of life of home-ventilated children and their primary caregivers plus the associated social and economic burdens: a prospective study. Archives of disease in childhood. 2016; 101(7):620–7. https://doi.org/10.1136/archdischild-2015-309796 PMID: 26940814

25. Rotondi AJ, Chelluri L, Sirio C, Mendelsohn A, Schulz R, Belle S, et al. Patients’ recollections of stressful experiences while receiving prolonged mechanical ventilation in an intensive care unit. Crit Care Med. 2002; 30(4):746–52. https://doi.org/10.1097/00003246-200204000-00004 PMID: 11940739

26. Chen H-C, Cheng W-H, Lin M-C. Care needs of lung-term ventilator-dependent patients from perspective of family members. Journal of respiratory therapy 2008; 7(2):1–19.

27. Bujang MA, Sa’at N, Sidik T, Joo LC. Sample size guidelines for logistic regression from observational studies with large population: Emphasis on the accuracy between statistics and parameters based on real life clinical data. The Malaysian journal of medical sciences: MJMS. 2018; 25(4):122–30. https://doi.org/10.21315/mjms2018.25.4.12 PMID: 30914854

28. Liu CJ, Kung PT, Chu CC, Chou WY, Shih CM, Tsai WC. Effect of the Integrated Prospective Payment Program on family members’ knowledge and acceptance of hospice care of patients on prolonged mechanical ventilation. Respiratory care. 2020; 65(4);464–474. https://doi.org/10.4187/respcare.06934 PMID: 31719192

29. Liu JF, Lu MC, Fang TP, Yu HR, Lin HL, Fang DL. Burden on caregivers of ventilator-dependent patients: A cross-sectional study. Medicine. 2017; 96(27):e7396. https://doi.org/10.1097/MD. 0000000000007396 PMID: 28662893

30. Douglas SL, Daly BJ. Caregivers of long-term ventilator patients: physical and psychological outcomes. Chest. 2003; 123(4):1073–81. https://doi.org/10.1378/chest.123.4.1073 PMID: 12684296

31. Servello A, Camellini C, Cicerchia M, Cerra E, Vigliotta MT, Vulcano A, et al. Physical and psychological stress in a group of Italian caregivers: a new medical emergency? A pilot study. Ig Sanita Pubbl. 2015; 71(5):489–98. PMID: 26722826
32. Evans R, Catapano MA, Brooks D, Goldstein RS, Avendano M. Family caregiver perspectives on caring for ventilator-assisted individuals at home. Canadian respiratory journal. 2012; 19(6):373–9. https://doi.org/10.1155/2012/452898 PMID: 23248801
33. Van Pelt DC, Milbrandt EB, Qin L, Weissfeld LA, Rotondi AJ, Schulz R, et al. Informal caregiver burden among survivors of prolonged mechanical ventilation. American journal of respiratory and critical care medicine. 2007; 175(2):167–73. https://doi.org/10.1164/rccm.200604-493OC PMID: 17068327
34. Yeh SH, Johnson MA, Wang ST. The changes in caregiver burden following nursing home placement. International journal of nursing studies. 2002; 39(6):591–600. https://doi.org/10.1016/s0020-7489(01)00055-4 PMID: 12100870
35. Nelson JE, Cox CE, Hope AA, Carson SS. Chronic critical illness. American journal of respiratory and critical care medicine. 2010; 182(4):446–54. https://doi.org/10.1164/rccm.201002-0210CI PMID: 20448093
36. Im K, Belle SH, Schulz R, Mendelsohn AB, Chelluri L. Prevalence and outcomes of caregiving after prolonged (> or = 48 hours) mechanical ventilation in the ICU. Chest. 2004; 125(2):597–606. https://doi.org/10.1378/chest.125.2.597 PMID: 14769744
37. Hung MC, Yan YH, Fan PS, Lin MS, Chen CR, Kuo LC, et al. Measurement of quality of life using EQ-5D in patients on prolonged mechanical ventilation: comparison of patients, family caregivers, and nurses. Quality of life research: an international journal of quality of life aspects of treatment, care and rehabilitation. 2010; 19(5):721–7.
38. Cox CE, White DB, Hough CL, Jones DM, Kahn JM, Olsen MK, et al. Effects of a personalized web-based decision aid for surrogate decision makers of patients with prolonged mechanical ventilation: A randomized clinical trial. Annals of internal medicine. 2019; 170(5):285–97. https://doi.org/10.7326/M18-2335 PMID: 30690645
39. Choi J, Hoffman LA, Schulz R, Ren D, Donahoe MP, Given B, et al. Health risk behaviors in family caregivers during patients’ stay in intensive care units: a pilot analysis. American journal of critical care: an official publication, American Association of Critical-Care Nurses. 2013; 22(1):41–5. https://doi.org/10.4037/ajcc2013830 PMID: 23283087
40. Dziadzko V, Dziadzko MA, Johnson MM, Gajic O, Karnatovskaia LV. Acute psychological trauma in the critically ill: Patient and family perspectives. General hospital psychiatry. 2017; 47:68–74. https://doi.org/10.1016/j.genhosppsych.2017.04.006 PMID: 28807140
41. Minton C, Batten L, Huntington A. The impact of a prolonged stay in the ICU on patients’ fundamental care needs. Journal of clinical nursing. 2018; 27(11–12):2300–10. https://doi.org/10.1111/jocn.14184 PMID: 29149460
42. Carson SS. Outcomes of prolonged mechanical ventilation. Current opinion in critical care. 2006; 12(5):405–11. https://doi.org/10.1097/01.ccx.0000244118.08753.dc PMID: 16943717
43. Mu PF, Wang KK, Chen YC, Tsay SF. A systematic review of the experiences of adult ventilator-dependent patients. JBI Libr Syst Rev. 2010; 8(8):344–81. https://doi.org/10.11124/jibs.2010.00001 PMID: 27829005