Research Square

Preprints are preliminary reports that have not undergone peer review.
They should not be considered conclusive, used to inform clinical practice,
or referenced by the media as validated information.

Factors Associated with Quality of Life among Primary Family Caregivers of Patients Receiving Long-Term Home Mechanical Ventilation: A Cross-Sectional Secondary Data Analysis in Taiwan

SHENG-HSIUNG HUANG
Asia University
HSING-YI LIN
Asia University
HUNG-EN LIAO
hcachair@gmail.com

Asia University
YU-LUNG CHIU
National Defense Medical University

Research Article

Keywords: Home mechanical ventilation, Primary caregivers, Quality of life, Caregiver burden, Social support

Posted Date: February 27th, 2026

DOI: https://doi.org/10.21203/rs.3.rs-8599435/v1

License: This work is licensed under a Creative Commons Attribution 4.0 International License. Read Full License

Additional Declarations: No competing interests reported.

Abstract

Background

With the increasing number of patients requiring prolonged mechanical ventilation (PMV), home mechanical ventilation (HMV) has become an increasingly important model of care. As a result, primary family caregivers are exposed to sustained and intensive caregiving responsibilities, raising growing concerns regarding their quality of life (QoL). This study aimed to examine the QoL of primary family caregivers of patients receiving long-term HMV and to analyze the associations between caregivers' QoL and demographic characteristics, caregiving burden, and social support.

Methods

This study conducted a secondary data analysis using questionnaire data obtained from a prior survey entitled "Caregiving Burden, Needs, and Decision-Making among Primary Family Caregivers of Patients Receiving Long-Term Home Mechanical Ventilation." A total of 410 valid questionnaires were analyzed. Participants were primary family caregivers residing in northern, central, and southern Taiwan who had provided care for patients receiving home mechanical ventilation for at least 60 days. Measures included caregivers' demographic characteristics, physical, psychological, social, and financial caregiving burden, social support (family, relatives, and other sources), and quality of life. Descriptive statistics, Pearson's correlation analysis, and multiple linear regression analyses were performed using SPSS version 22.0.

Results

Most caregivers were female, middle-aged or older, and co-residing with the patient. The average daily caregiving time was 13.25 hours. The mean overall QoL score was 2.94, indicating a level between "poor" and "moderate." Pearson's correlation analysis showed a significant negative association between daily caregiving time and QoL ($r = -0.285$, $p < 0.001$). Multiple regression analyses revealed that, after controlling for demographic variables, physical burden, social burden, and financial burden were all significantly and negatively associated with QoL, whereas family support demonstrated a stable and significant positive association. In contrast, psychological burden did not show an independent significant effect after other caregiving burden and social support variables were included in the model. Although household income was positively associated with QoL in the initial model, this association became non-significant after caregiving burden and social support were simultaneously considered.

Conclusions

Primary family caregivers of patients receiving long-term HMV are chronically exposed to high-intensity caregiving demands, and their quality of life is primarily shaped by the level of caregiving burden and the availability of family support. The findings suggest that primary caregivers should be recognized as a high-risk population with independent health risks. From both practice and policy perspectives, in addition to financial assistance, it is essential to strengthen respite services, family support, and the integration of healthcare and long-term care systems in order to effectively reduce caregiving burden, improve caregivers' quality of life, and enhance the sustainability of home mechanical ventilation care systems.

Introduction

Prolonged mechanical ventilation (PMV) is internationally defined as the use of mechanical ventilation for at least 6 hours per day for 21 consecutive days or longer, according to the standards of the National Association for Medical Direction of Respiratory Care (NAMDRC). This definition also serves as the primary criterion for identifying long-term ventilator use under Taiwan's National Health Insurance system. According to statistics from the National Health Insurance Administration, a total of 192,034 new patients received mechanical ventilation in Taiwan in 2024; among them, 23,955 patients used ventilatory support for 22–63 days, and 5,852 patients required ventilation for 64 days or longer. Taiwanese scholars have noted that the global population of patients requiring PMV continues to increase, and international studies similarly report a steady upward trend in the number of individuals dependent on long-term mechanical ventilation over recent decades, imposing a substantial and growing burden on healthcare systems worldwide.

Estimates based on Taiwan's National Health Insurance database and related academic studies suggest that more than 20,000 patients annually are dependent on long-term mechanical ventilation, highlighting the magnitude of healthcare demand. Although systematic public

statistics on the number of patients receiving home-based care are limited, empirical studies indicate that among patients receiving home mechanical ventilation (HMV), approximately 60–70% require ventilatory support for at least 19 hours per day, around 45% have been using ventilators for more than three years, and nearly 80% have experienced multiple hospital admissions. These findings reflect the high level of dependency and intensive healthcare resource utilization associated with this population. As home-based care expands, the demand placed on family caregivers increases accordingly, exposing primary family caregivers to substantial financial, physical, psychological, and social role-related burdens.

In response to the growing healthcare demand and the need to improve care efficiency, Taiwan has implemented an integrated prospective payment system for ventilator-dependent patients under the National Health Insurance program, extending care from hospital settings to patients' homes. This policy aims to reduce healthcare resource consumption associated with prolonged institutionalization and to lower the risk of hospital-acquired infections. However, while home-based care may alleviate pressure on healthcare institutions, it simultaneously shifts a potential proportion of ongoing caregiving responsibilities to families, thereby intensifying the physical, psychological, and emotional stress experienced by primary family caregivers. Consequently, the present study conducts a secondary analysis to examine the quality of life (QoL) of primary family caregivers of patients receiving long-term home mechanical ventilation (HMV) in Taiwan.

Specifically, this study aims to: (1) describe the level of QoL among primary family caregivers of long-term HMV patients; and (2) examine the independent associations of caregivers' demographic characteristics, multidimensional caregiving burden (physical, psychological, social, and financial), and multiple sources of social support (including family members, relatives, and professional or organizational support) with caregivers' QoL.

By elucidating how caregiving burden and social support jointly shape caregivers' QoL, the findings are expected to address an important gap in the literature and to inform relevant authorities in the revision and development of support service programs for family caregivers of patients receiving long-term HMV.

Methods

1. Study Design and Data Source

This study employed a secondary data analysis design. The data were derived from a questionnaire database established by a previous research project titled "Analysis of the burden, help need, and ventilator removal decision in family caregivers of long-term ventilator-dependent home care patients."[2] The database was developed under the supervision of Professor Hung-En Liao, Department of Healthcare Administration, Asia University, and data were collected by trained graduate students.

The original questionnaire covered multiple caregiving-related domains. The internal consistency of the subscales was satisfactory, with Cronbach's alpha coefficients ranging from 0.80 to 1.00. Content validity was assessed through expert review, with all Content Validity Index (CVI) values exceeding 0.85, indicating good reliability and validity. The original study was approved by the Institutional Review Board of Dalin Tzu Chi Hospital, Jen-Ai Healthcare Foundation (IRB No. 108 – 88). The present study conducted a secondary analysis of fully de-identified data and did not involve any personally identifiable information.

Data were collected between October 16 and November 30, 2020, and a total of 410 valid questionnaires were included in the analysis. The study participants were primary family caregivers of patients receiving long-term home mechanical ventilation. The inclusion criteria were as follows: (1) the patient was in a stable condition and had been receiving mechanical ventilation at home for at least 60 days; (2) the primary family caregiver was a Taiwanese national, aged 18 years or older, with full legal capacity and provided informed consent to participate; and (3) participants were recruited from northern Taiwan (north of Hsinchu), central Taiwan (Miaoli, Taichung, Changhua, and Nantou), and southern Taiwan (Yunlin, Chiayi, Tainan, Kaohsiung, and Pingtung).

2. Conceptual Framework

The conceptual framework of this study was developed with caregivers' quality of life as the dependent variable, integrating three major categories of independent variables: demographic characteristics, caregiving burden, and social support (Fig. 1). By simultaneously incorporating demographic variables, caregiving burden, and social support into multiple regression models, the study systematically examined the relative contribution of each domain to caregivers' quality of life and clarified the roles of different types of burden and support within the context of long-term home mechanical ventilation.

3. Measures

This study extracted selected items from the original questionnaire used in the aforementioned research project. The original instrument consisted of six main sections, as described below:

1. Basic characteristics of patients receiving long-term home mechanical ventilation, including sex, age, and industry of employment.
2. Basic characteristics of primary family caregivers, including caregivers' expectations regarding the patient and their willingness to continue providing home-based care.
3. Caregiving burden of primary family caregivers, assessing caregivers' perceived burden across four dimensions: physical burden, psychological burden, social burden, and financial burden.
4. Social support of primary family caregivers, assessing the level of instrumental and emotional support received from family members, relatives, healthcare professionals, and social service organizations (including associations).
5. Quality of life of primary family caregivers, assessing caregivers' perceptions of their overall quality of life and health status.
6. Caregiving needs of primary family caregivers, assessing caregivers' perceived needs across four domains: manpower support, psychological support, financial support, and care-related support.

4. Data Processing and Statistical Analysis

All data processing and statistical analyses were performed using SPSS version 22.0. Both descriptive and inferential statistical analyses were conducted. Descriptive statistics, including frequency distributions, means, and standard deviations, were used to summarize caregivers' demographic characteristics (including sex, age, relationship with the patient, marital status, educational level, employment status, adequacy of household income to meet living needs, socioeconomic security, co-residence with the patient, knowledge of the patient's illness, and expectations regarding the patient), as well as caregiving burden and social support.

This study was based on a secondary database, and the final analytic sample consisted of 410 valid cases.

Inferential analyses included independent-samples t tests and one-way analysis of variance (ANOVA) to examine differences in caregiving burden, social support, and quality of life across demographic subgroups. Multiple linear regression analyses were subsequently performed to investigate the associations between demographic variables, different dimensions of caregiving burden, various sources of social support, and caregivers' quality of life. Normality of continuous variables was examined prior to analysis using the Kolmogorov–Smirnov and Shapiro–Wilk tests. Regression results are presented as standardized regression coefficients (standardized β).

Results

1. Demographic Characteristics of Primary Family Caregivers

Descriptive statistical analyses were conducted using selected items from the original questionnaire. The results are presented in Table 1. Among the 410 primary family caregivers, the majority were female (n = 285, 69.5%), while 125 were male (30.5%). With regard to age distribution, most caregivers were between 31–50 years (n = 143, 34.9%) or 51–70 years (n = 193, 47.1%), indicating that caregiving responsibilities were primarily assumed by middle-aged and early older adults.

In terms of the caregivers' relationship with the patient, 98 caregivers (23.9%) were spouses, 69 (16.8%) were parents or older relatives, 166 (40.5%) were adult children or grandchildren, and 77 (18.8%) were siblings, with lineal descendants representing the largest proportion. Most caregivers were married (72.9%). Regarding educational attainment, nearly half had a medium level of education (senior high school or junior college; 48.5%). More than half of the caregivers were unemployed (n = 235, 57.3%), while 16.8% were employed part-time and 25.9% full-time.

Over half of the caregivers reported that their household income was adequate at a moderate level (52.4%), whereas 20.7% reported insufficient income. Regarding knowledge of home-based care for ventilator-dependent patients, the largest proportion of caregivers reported a moderate level of knowledge (scores 6–10; 40.7%). With respect to expectations regarding the patient's duration of ventilator independence, the most common expectation was 7–12 hours per day (43.4%).

Table 1
Demographic characteristics of primary family caregivers (N = 410)

Variables	n (%)	Variables	n (%)
Sex		**Employment status**	
Male	125 (30.5%)	Unemployed	235 (57.3%)
Female	285 (69.5%)	Part-time	69 (16.8%)
Age		Full-time	106 (25.9%)
< 30 years	21 (5.1%)	**Household income**	
31–50 years	143 (34.9%)	Sufficient	110 (26.8%)
51–70 years	193 (47.1%)	Moderate	215 (52.4%)
> 70 years	53 (12.9%)	Insufficient	85 (20.7%)
Relationship to the patient		**Co-residing with the patient**	
Spouse	98 (23.9%)	Yes	381 (92.9%)
Older relative	69 (16.8%)	No	29 (7.1%)
Grandchildren	166 (40.5%)	**Knowledge of home-based care for the patient's illness**	
Siblings	77 (18.8%)	Low (0–5 points)	88 (21.5%)
Marital status		Moderate (6–10 points)	167 (40.7%)
Unmarried	111 (27.1%)	High (11–12 points)	155 (37.8%)
Married	299 (72.9%)	**Expected duration of ventilator independence**	
Educational level		1 ~ 6hr	77(18.8%)
Low	116 (28.3%)	7 ~ 12hr	178(43.4%)
Medium	199 (48.5%)	13 ~ 18hr	66(16.1%)
High	95 (23.2%)	19 ~ 24hr	89(21.7%)

2. Association Between Daily Caregiving Time and Quality of Life

According to Table 2 and Table 3, the mean quality of life score among primary family caregivers was 2.94, indicating a level between "poor" and "moderate," with a tendency toward moderate quality of life. The average daily caregiving time was 13.25 hours. Pearson's correlation analysis demonstrated a significant negative association between daily caregiving time and quality of life ($r = -0.285$, $p < 0.001$), indicating that longer caregiving time was associated with poorer quality of life.

Table 2
Descriptive statistics of quality of life and daily caregiving time

Variable	Mean	SD	N
Quality of life	2.94	0.756	410
Daily caregiving time (hours)	13.249	7.6306	410

Table 3
Pearson's correlation between daily caregiving time and quality of life

		Daily caregiving time (hours)
Quality of life	Pearson's correlation coefficient	−0.285**
	Significance (two-tailed)	< 0.001
	N	410
Note: p < 0.01 (two-tailed).		

3. **Hierarchical Regression Results: Model Fit, Diagnostics, and Effects of Demographic Characteristics, Caregiving Burden, and Social Support on Quality of Life (Models 1–4)**

To evaluate the adequacy of the regression models, overall model fit indices (adjusted R^2) and F tests for model significance were reported as shown in Table 4. Regression diagnostics were conducted to assess key model assumptions, including the normality of residuals, independence of residuals (Durbin–Watson statistic), and homoscedasticity (inspection of residual patterns). In addition, multicollinearity was evaluated using tolerance values and variance inflation factors (VIFs) to ensure the stability and reliability of the regression coefficient estimates. The corresponding results are presented in Table 4.

Across Models 1–4, all regression models were statistically significant (all $p < .001$). Model fit improved overall, with Model 4 demonstrating the best explanatory power (adjusted $R^2 = 0.431$), followed by Model 2 (0.390), Model 3 (0.234), and Model 1 (0.105). Durbin–Watson statistics were close to 2.0 (1.975–2.053), suggesting no substantial autocorrelation of residuals. Multicollinearity was not problematic, as VIF values remained below 3.279 and tolerance values were generally above 0.305.

Multiple regression analyses were conducted to examine the effects of demographic characteristics, caregiving burden, and social support on caregivers' quality of life. Four regression models were constructed using different combinations of variables, as described below.

1. Model 1: In Model 1 (adjusted $R^2 = 0.105$, $p < 0.001$), household income was positively associated with caregivers' quality of life (QoL) (Std. $\beta = 0.341$, $p < 0.001$). Diagnostic statistics suggested no substantial autocorrelation of residuals (Durbin–Watson = 2.052) and no evidence of problematic multicollinearity (VIF range: 1.022–1.525; tolerance range: 0.656–0.979); standardized residuals ranged from − 3.299 to 2.844.
2. Model 2: In Model 2 (adjusted $R^2 = 0.390$, $p < 0.001$), household income (Std. $\beta = 0.110$, $p = 0.024$) and knowledge of the patient's illness (Std. $\beta = 0.102$, $p = 0.013$) were positively associated with QoL, whereas physical burden (Std. $\beta = −0.177$, $p = 0.012$), social burden (Std. $\beta = −0.251$, $p < 0.001$), and financial burden (Std. $\beta = −0.181$, $p = 0.040$) were independently associated with lower QoL. Durbin–Watson was 1.984, and multicollinearity was acceptable (VIF range: 1.025–3.266; tolerance range: 0.306–0.976); standardized residuals ranged from − 4.265 to 2.780.
3. Model 3: In Model 3 (adjusted $R^2 = 0.234$, $p < 0.001$), household income (Std. $\beta = 0.257$, $p < 0.001$), family support (Std. $\beta = 0.269$, $p < 0.001$), and support from relatives (Std. $\beta = 0.149$, $p = 0.018$) were positively associated with QoL. Durbin–Watson was 2.053, and no problematic multicollinearity was observed (VIF range: 1.027–2.093; tolerance range: 0.478–0.974); standardized residuals ranged from − 3.698 to 2.539.
4. Model 4: In Model 4 (adjusted $R^2 = 0.431$, $p < 0.001$), physical burden (Std. $\beta = −0.192$, $p = 0.005$), social burden (Std. $\beta = −0.194$, $p = 0.002$), and financial burden (Std. $\beta = −0.168$, $p = 0.006$) remained independently associated with lower QoL, whereas family support was positively associated with QoL (Std. $\beta = 0.126$, $p = 0.007$). Durbin–Watson was 1.975, and multicollinearity remained acceptable (VIF range: 1.030–3.279; tolerance range: 0.305–0.971); standardized residuals ranged from − 4.546 to 2.665.

Table 4
Multiple regression analysis of demographic characteristics, caregiving burden, and social support in relation to caregivers' quality of life (N = 410)

Variable	Model 1			Model 2			Model 3			Model 4		
	Std. β	t	p	Std. β	t	p	Std. β	t	p	Std. β	t	p
Demographic characteristics												
Sex	-0.03	-0.634	0.527	0.072	1.781	0.076	-0.031	-0.701	0.484	0.061	1.550	0.122
Caregiver age	-0.06	-1.039	0.299	-0.004	-0.074	0.941	-0.059	-1.094	0.275	-0.02	-0.044	0.965
Relationship to the patient	0.046	0.885	0.376	-0.024	-0.561	0.575	0.064	1.335	0.183	-0.001	-0.031	0.975
Marital status	0.019	0.372	0.710	0.001	0.028	0.978	0.014	0.285	0.776	0.001	0.032	0.974
Educational level	0.009	0.162	0.871	0.062	1.337	0.182	-0.016	-0.309	0.757	0.046	1.008	0.314
Employment status	0.020	0.422	0.673	0.033	0.833	0.405	0.025	0.556	0.579	0.030	0.785	0.433
Household income	0.341***	6.884	< 0.001	0.110*	2.259	0.024	0.257***	5.436	< 0.001	0.082	1.717	0.087
Co-residence with the patient	-0.014	-0.287	0.774	-0.015	-0.371	0.711	-0.049	-1.105	0.27	-0.040	-1.018	0.309
Expected duration of ventilator independence	0.018	0.370	0.711	0.038	0.974	0.331	0.022	0.511	0.61	0.039	1.034	0.302
Knowledge of the patient's illness	-0.03	-0.061	0.952	0.102*	2.501	0.013	-0.036	-0.787	0.432	0.065	1.624	0.105
Caregiving burden												
Physical burden				-0.177*	-2.535	0.012				-0.192**	-2.840	0.005
Psychological burden				-0.079	-1.179	0.239				-0.055	-0.846	0.398
Social burden				-0.251***	-4.043	< 0.001				-0.194**	-3.165	0.002
Financial burden				-0.181*	-2.901	0.04				-0.168**	-2.777	0.006
Social support												
Family support							0.269***	5.151	< 0.001	0.126**	2.688	0.007
Support from relatives							0.149*	2.376	0.018	0.078	1.429	0.154
Support from other sources							0.015	0.252	0.801	0.072	1.353	0.177

Variable	Model 1	Model 2	Model 3	Model 4
Model fit				
Adjusted R^2	0.105	0.390	0.234	0.431
Model significance (p-value)	< 0.001	< 0.001	< 0.001	< 0.001

Note: All models were estimated using N = 410.

Variable	Model 1			Model 2			Model 3			Model 4		
	Std. β	t	p	Std. β	t	p	Std. β	t	p	Std. β	t	p
Residual diagnostics												
Durbin–Watson				2.052			1.984			2.053		
Standardized residuals (min–max)				−3.299 to 2.844			−4.265 to 2.780			−3.698 to 2.539		
Std. error of the estimate				0.706			0.580			0.662		
Multicollinearity												
Tolerance (min–max)				0.656 to 0.979			0.306 to 0.976			0.478 to 0.974		
VIF (min–max)				1.022 to 1.525			1.025 to 3.266			1.027 to 2.093		
Note: All models were estimated using N = 410.												

*p < .05; **p < .01; ***p < .001.

Discussion

1. Psychological burden and its association with caregivers' quality of life

In this study, physical burden, social burden, and financial burden were significantly and negatively associated with caregivers' quality of life. In contrast, psychological burden was not statistically significant either in the model including caregiving burden only (Model 2, Std. β = −0.079, p = 0.239) or in the fully adjusted model controlling for demographic characteristics and social support (Model 4, Std. β = −0.055, p = 0.398). This finding suggests that when multiple types of burden and social support are considered simultaneously, the independent explanatory contribution of psychological burden to quality of life may be limited. Such a pattern differs from the intuitive expectation that greater psychological stress is invariably associated with poorer quality of life, and therefore warrants further interpretation in light of prior literature and caregiving contexts.

Psychological burden often represents a composite reflection of other objective stressors and may substantially overlap with physical, social, and financial burdens.[8] reported that caregivers of ventilator-dependent patients frequently linked anxiety and depressive experiences directly to tangible conditions such as prolonged caregiving hours, the inability to leave the patient unattended, and loss of income, indicating that psychological distress is commonly driven by caregiving intensity, physical depletion, and financial strain rather than arising independently. Accordingly, in the present models, once these dimensions of burden were entered, the incremental explanatory power of psychological burden was likely attenuated.

In addition, prior studies indicate that objective burden and subjective psychological burden do not necessarily align. Families of patients receiving noninvasive mechanical ventilation (NIMV) have been shown to experience substantial objective burdens in social relationships and household management, yet report relatively low subjective burden [12]. This discrepancy suggests that caregivers may frame caregiving as an obligation or responsibility, thereby downplaying psychological distress.

Recent research further suggests that the influence of mental health on quality of life among home mechanical ventilation caregivers is often not expressed through a single direct pathway but rather operates indirectly through multiple structural and process-related mechanisms. That is, psychological burden may not exert a direct effect on quality of life; instead, as caregiving time accumulates, psychological strain may translate into other measurable forms of burden or be moderated by family and social support, thereby affecting quality of life indirectly.

Social support and coping strategies have been shown to explain caregivers' overall stress experience more effectively than a single psychological stress measure alone [11]. Consistent with this perspective, depression and anxiety may influence caregivers' quality of life through broader caregiving-related processes—such as accumulated fatigue, social isolation, and functional limitations—rather than through a single direct pathway [3].

Taken together, the non-significant association of psychological burden in the regression models likely reflects that its effects were transformed into, and absorbed by, the physical, social, and financial dimensions of caregiving burden, and/or were mediated or buffered by social support and coping strategies, rather than indicating that psychological factors are unimportant in caregiving. Therefore, clinical and policy practice should not prioritize interventions solely based on statistical significance. In addition to reducing caregiving time and financial strain and strengthening family and social support, routine emotional assessment and psychological support mechanisms should be incorporated to prevent psychological distress from becoming "invisible" in quantitative analyses while continuing to undermine caregivers' health and willingness to provide long-term care in real-life settings.

2. The mediating mechanisms of social support in caregivers' quality of life

This study found that when social support and caregiving burden were entered into the regression model simultaneously, the effect of social burden—previously significant when only burden variables were included—was substantially attenuated. This pattern suggests that part of the variance in quality of life originally explained by social burden may overlap with, or be shared with, the support structure represented by social support. Such a result implies that social support may intervene in the relationship between social burden and quality of life, such that some of the variance initially attributed to social burden is partially reallocated through caregiving processes that are modified by support.

Recent empirical evidence likewise indicates that social support often influences caregivers' well-being through indirect pathways—such as caregiving burden, self-efficacy, or coping strategies—rather than through direct effects alone. In studies of family caregivers, the independent explanatory contribution of perceived social support has been shown to decrease substantially after controlling for caregiving burden, indicating that the benefits of support are highly contingent on the underlying caregiving stress structure [9]. Similarly, social support has been reported to function primarily as a mediating mechanism between caregiving burden and caregivers' quality of life, rather than exerting a strong independent predictive effect on quality of life [13], supporting the attenuation of the relative-support effect observed in the present multivariable models.

In highly intensive long-term home mechanical ventilation care contexts, these mechanisms may be particularly salient. Family and relative support has been shown to provide emotional and practical assistance; however, such support is often accompanied by increased involvement in caregiving tasks, particularly in energy-demanding activities such as nighttime care, physical repositioning, and prolonged standby [11]. This increased participation may intensify physical fatigue and sleep deprivation. Accordingly, once physical burden is included in analytical models, the apparent protective effects of support sources may shift toward indirect or mediated pathways rather than emerging as independent main effects. This interpretation is consistent with evidence from a meta-analysis indicating that the protective effects of social support on quality of life should be understood in relation to whether such support is effectively translated into reductions in caregiving burden, particularly subjective burden [5].

Overall, the findings suggest that support from relatives in long-term home mechanical ventilation may have a dual nature—both "supportive" and "burden-amplifying." If such support is primarily expressed as shared caregiving responsibility without introducing external professional resources or reducing actual caregiving hours, its positive effects may be offset by increased physical burden. This finding implies that future caregiver support policies and interventions should not merely aim to "increase family or relative support," but should simultaneously assess whether support translates into tangible reductions in caregivers' physical depletion and caregiving intensity in order to improve quality of life effectively.

3. Positioning primary family caregivers as a high-risk population: empirical evidence and implications for intervention

This study found that primary family caregivers of patients receiving home mechanical ventilation across multiple counties and cities in Taiwan were predominantly middle-aged or older women co-residing with the patient, providing more than 13 hours of care per day over a prolonged period. Physical, social, and financial burdens were significantly associated with poorer quality of life, while only family support showed a protective association. This pattern indicates that primary caregivers are not merely providers of informal care, but constitute a population chronically exposed to multiple stressors and at elevated risk for health deterioration. From a preventive medicine perspective, they meet the criteria of a "high-risk population" and should be proactively identified and engaged before the emergence of severe symptoms or major psychological problems.

International evidence has reported similar patterns. Longitudinal interview studies of family caregivers of patients requiring long-term mechanical ventilation have documented frequent sleep disruption, anxiety, fatigue, and emotional distress, as well as substantially lower

health-related quality of life compared with the general population [4]. In addition, synthesized evidence indicates that informal caregivers often experience high psychological stress, social isolation, and elevated physical health risks, with adverse effects becoming more pronounced as caregiving hours increase [3]. Large-scale surveillance data from the United States further demonstrate that, compared with non-caregivers, family caregivers have a higher prevalence of frequent mental distress and lifetime diagnosed depression, with a cumulative worsening trend as caregiving responsibilities accumulate [6]. Collectively, these findings underscore the heightened risks of psychological distress and depression associated with prolonged caregiving burden and responsibility, and support the argument that caregivers should be regarded as a high-risk population for mental health and chronic disease prevention, rather than relying on a passive approach that waits for caregivers to seek help after substantial risk accumulation.

At the intervention level, accumulating evidence supports multi-component psychological and behavioral strategies for reducing caregivers' psychological distress and improving health outcomes. Systematic reviews and meta-analyses have consistently reported that psychoeducation, cognitive behavioral therapy (CBT), multi-component integrated programs, and mindfulness-based interventions can effectively reduce caregivers' stress, depression, and anxiety and improve self-rated health and sleep quality across caregiving populations [10, 14, 5]. Recent studies further suggest that mindfulness-oriented interventions can buffer the adverse effects of psychological stress on quality of life under high-burden caregiving conditions. Moreover, telephone- or internet-delivered formats offer clear advantages in accessibility and feasibility, making them particularly suitable for long-term home-based caregivers. [1, 11]

Taken together, caregiving burden and family support appear to be the most proximal determinants of caregivers' quality of life. In practice, caregiver burden and emotional status should be integrated into routine assessments in ventilator outpatient services, discharge planning, home nursing, and long-term care case management, alongside brief screening and risk stratification mechanisms. Family-based interventions—such as family meetings, role coordination, and communication training—should be developed to prevent caregiving responsibilities from becoming overly concentrated on a single individual. For caregivers experiencing high stress or suspected emotional difficulties, clear and accessible referral pathways should be established to facilitate timely access to CBT, mindfulness-based, or integrative psychological interventions delivered by psychologists or psychiatrists. At the system level, mapping the density of healthcare and long-term care resources and developing cross-organizational, integrated home respiratory care networks may enhance the continuity and quality of professional home-based services, consistent with system-level recommendations for integrated and interprofessional care in long-term home mechanical ventilation [7].

Overall, this study highlights that primary family caregivers of patients receiving home mechanical ventilation should be recognized as a high-risk population with independent health needs and rights, rather than as an invisible "care resource." Integrating preventive and intervention strategies across individual, family, and system levels may stabilize caregivers' stress and emotional well-being before health deterioration and caregiving breakdown occur, while also reducing care inequities arising from regional and structural differences and strengthening the safety and sustainability of home respiratory care systems.

4. Study limitations

Several limitations should be acknowledged. First, due to the cross-sectional design, this study can only identify associations among variables and cannot establish causal relationships. This design also limits the ability to capture longitudinal changes in caregivers' psychological burden and quality of life over time.

Second, as this secondary analysis relied on purposive sampling from an existing database, the sample may be subject to selection bias related to the original recruitment criteria and regional coverage, which may limit the generalizability of the findings to other caregiver populations or care settings.

Third, most key variables—including caregiving burden, social support, and quality of life—were assessed using self-reported questionnaires, which may introduce information bias and social desirability bias, particularly in cultural contexts where emotional distress is less openly expressed. Moreover, because both independent and dependent variables were collected using the same self-report method at a single time point, the results may be influenced by common method variance, potentially inflating observed associations.

In addition, although the original instruments demonstrated acceptable reliability and content validity, not all adapted scales were re-validated within the current dataset, which may have affected measurement precision.

Finally, no formal sensitivity analyses were conducted to assess the robustness of the findings under alternative model specifications or assumptions. Future studies are encouraged to incorporate sensitivity analyses, longitudinal designs, and mixed-methods approaches to better address potential biases and to more comprehensively capture the dynamic processes underlying caregiving burden and quality of

life. External contextual factors, such as major public health events or policy changes, may also be included as covariates to strengthen explanatory power.

Conclusions

Using quantitative secondary data analysis, this study systematically examined the quality of life of primary family caregivers of patients receiving long-term home mechanical ventilation and its associated factors. The findings indicate that caregiving burden and family support are the core determinants of caregivers' quality of life. Specifically, physical, social, and financial burdens showed stable and significant negative associations with quality of life, whereas family support demonstrated an independent and sustained protective association. In contrast, although household income was significantly associated with quality of life in the initial model, the association became non-significant after caregiving burden and social support were included simultaneously. This suggests that caregivers' quality of life is not determined solely by economic conditions, but is indirectly shaped by the level of burden embedded in day-to-day caregiving experiences and by the accessibility and functionality of supportive resources.

The sample profile further indicated that most caregivers were middle-aged or older women co-residing with the patient, providing more than 13 hours of care per day over an extended period, reflecting chronic exposure to substantial physical depletion, restricted social roles, and accumulated financial stress. Consistent with both domestic and international evidence, the results underscore that under high-intensity home mechanical ventilation care contexts, caregiving burden exerts a direct and strong negative impact on quality of life, while family support can partially buffer the adverse effects of high burden; however, its protective effects must be interpreted within the structure of actual caregiving demands.

Overall, this study emphasizes that primary family caregivers of patients receiving home mechanical ventilation should be recognized as a high-risk population with independent health risks. Maintaining caregivers' quality of life depends on whether caregiving burden can be effectively managed and whether family support is stable and functionally meaningful. Therefore, future policy and practice should not rely solely on financial assistance as the core strategy. Instead, it is essential to strengthen respite services, family support, and cross-sector resource integration mechanisms, thereby shifting part of the structural caregiving pressure from families back to formal care systems. Such an approach may improve caregivers' quality of life and enhance the stability and sustainability of home mechanical ventilation care systems.

Declarations

Ethics approval and consent to participate

The original research project, Analysis of the burden, help need, and ventilator removal decision in family caregivers of long-term ventilator-dependent home care patients, was approved by the Institutional Review Board of Dalin Tzu Chi Hospital, Jen-Ai Healthcare Foundation (IRB No. 108-88), and was conducted in accordance with the ethical standards of the Declaration of Helsinki and the Human Subjects Research Act of Taiwan. Written informed consent was obtained from all participants prior to their participation in the study.

Consent for publication

Not applicable.

Availability of data and materials

All data generated or analysed during this study are included in this published article [and its supplementary information files].

Competing interests

The authors declare that they have no competing interests.

Funding

This study received no external funding.

Authors' contributions

Sheng-Hsiung Huang conceptualized the study, conducted data analysis, and led the organization and writing of the manuscript.

Hsing-Yi Lin assisted with research discussions and contributed to manuscript revision and editing.

Dr. Liao led the editing process and was responsible for the final revision of the manuscript.

Yu-Lung Chiu contributed expertise in health promotion and policy research and provided scholarly input to the manuscript.

All authors reviewed and approved the final manuscript.

Acknowledgements

Not applicable.

References

1. Boyt N, Ho AK, Morris-Bankole H, Sin J. Internet-facilitated interventions for informal caregivers of patients with neurodegenerative disorders: Systematic review and meta-analysis. Digit health. 2022;8:20552076221129069. https://doi.org/10.1177/20552076221129069.
2. Chen Y-L. (2021). Analysis of the burden, help need, and ventilator removal decision in family caregivers of long-term ventilator-dependent home care patients (Unpublished master's thesis). Asia University, Taichung, Taiwan. [in Chinese].
3. Cichoń J, Homa M, Płaszewska-Żywko L, Kózka M. Psychosocial Well-Being of Informal Caregivers of Adults Receiving Home Mechanical Ventilation: A Scoping Review. J Clin Med. 2025;14(17):6294. https://doi.org/10.3390/jcm14176294.
4. Dale CM, Carbone S, Istanboulian L, Fraser I, Cameron JI, Herridge MS, Rose L. Support needs and health-related quality of life of family caregivers of patients requiring prolonged mechanical ventilation and admission to a specialised weaning centre: A qualitative longitudinal interview study. Intensive Crit Care Nurs. 2020;58:102808. https://doi.org/10.1016/j.iccn.2020.102808.
5. del-Pino-Casado R, Frías-Osuna A, Palomino-Moral PA, Ruzafa-Martínez M, Ramos-Morcillo AJ. Social support and subjective burden in caregivers of adults and older adults: A meta-analysis. PLoS ONE. 2018;13(1):e0189874. https://doi.org/10.1371/journal.pone.0189874.
6. Kilmer G, Omura JD, Bouldin ED, et al. Changes in Health Indicators Among Caregivers — United States, 2015–2016 to 2021–2022. MMWR Morb Mortal Wkly Rep. 2024;73:740–6. http://dx.doi.org/10.15585/mmwr.mm7334a2.
7. Klingshirn H, Gerken L, Hofmann K, et al. How to improve the quality of care for people on home mechanical ventilation from the perspective of healthcare professionals: a qualitative study. BMC Health Serv Res. 2021;21:774. https://doi.org/10.1186/s12913-021-06743-3.
8. Liu J-F, Msa M-CM, Fang T-P, Msc H-R, Lin MD. Hui-Ling Msc,d,f,*; Fang, Der-Long PhDb. Burden on caregivers of ventilator-dependent patients: A cross-sectional study. Medicine 96(27):p e7396, July 2017. | 10.1097/MD.0000000000007396
9. Nemcikova M, Katreniakova Z, Nagyova I. Social support, positive caregiving experience, and caregiver burden in informal caregivers of older adults with dementia. Front public health. 2023;11:1104250. https://doi.org/10.3389/fpubh.2023.1104250.
10. O'Toole MS, Zachariae R, Renna ME, Mennin DS, Applebaum A. Cognitive behavioral therapies for informal caregivers of patients with cancer and cancer survivors: a systematic review and meta-analysis. Psycho-oncology. 2017;26(4):428–37. https://doi.org/10.1002/pon.4144.
11. Płaszewska-Żywko L, Fajfer-Gryz I, Cichoń J, Kózka M. Burden, social support, and coping strategies in family caregivers of individuals receiving home mechanical ventilation: a cross-sectional study. BMC Nurs. 2024;23(1):346. https://doi.org/10.1186/s12912-024-02024-6.
12. Tsara V, Serasli E, Voutsas V, Lazarides V, Christaki P. Burden and Coping Strategies in Families of Patients under Noninvasive Home Mechanical Ventilation. Respiration 1 Febr. 2006;73(1):61–7. https://doi.org/10.1159/000087460.
13. Zhang Y, Li J, Zhang Y, Chen C, Guan C, Zhou L, Zhang S, Chen X, Hu X. Mediating effect of social support between caregiver burden and quality of life among family caregivers of cancer patients in palliative care units. Eur J Oncol nursing: official J Eur Oncol Nurs Soc. 2024;68:102509. https://doi.org/10.1016/j.ejon.2024.102509.
14. Zhou S, Wang Y, Wang Q, Yang G, Ren H, Bao Y. A meta-analysis of the effects of cognitive behavioral therapy on quality of life and negative emotions of informal cancer caregivers. Front Psychiatry. 2022;13:979158. https://doi.org/10.3389/fpsyt.2022.979158.

Figures

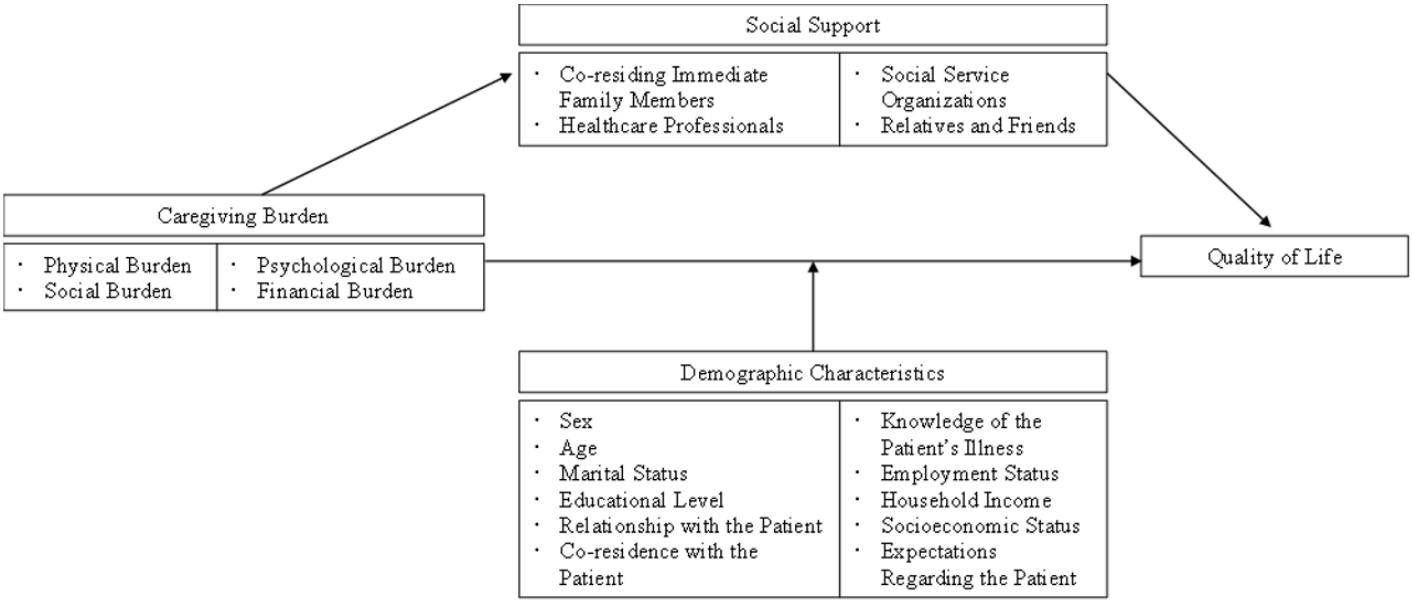


Figure 1

Conceptual Framework of the Study