



## “A STUDY OF THE BURDEN ON CAREGIVERS OF VENTILATOR-DEPENDENT PATIENTS”

**Dr. Imran Shivji**

Consultant Psychiatrist, Chandrapur.

**Dr. Pranay Gandhi**

Assistant professor in community medicine, GMC, Chandrapur.

### ABSTRACT

The present study investigated the burden on caregivers of PMV patients. This cross-sectional study 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 2016.

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.

**KEYWORDS :** emergency burden

### Introduction:

The 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.[1,2] 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.[3] 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%.[1]

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.[4] 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.[5,6] Most PMV patients and families in Taiwan prefer to reside in institutional care centers, and home care is not commonly accepted.[7] 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.[5,8–11] 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.[10,12–14] 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.

### Materials and methods:

The present study was conducted between June and December 2016 in a tertiary Hospital in central India, 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. 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.

### 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%.

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 home caregivers than RCW caregivers ( $12.10 \pm 3.65$  vs  $10.50 \pm 4.25$ ).

### Discussion:

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.”[15] However, studies have shown similar results. For example, Douglas and Daly[16] observed that caregivers of long-term ventilator-dependent 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. [6,17] 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[16] moreover reported that the health status upon caregivers of PMV patients encountered a higher degree of health problems. [16]

The present results revealed that caregivers believed that their health status is extremely poor. Hickman and Douglas[18] found that the health status of PMV patients gradually worsens with increased risks.

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.”[19]

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.[20,21]

A previous study demonstrated a significant relationship between caregivers' disease awareness and decreased burden on caregivers. [22] 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.[20,23] 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.[24]

**Tables:**

**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%)	

**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%)	

**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*

**References:**

1. Nevins ML, Epstein SK. Weaning from prolonged mechanical ventilation. *Clin Chest Med* 2001;22:13–33.
2. 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:R102.
3. Gracey DR. Costs and reimbursement of long-term ventilation. *Respir Care Clinf N Am* 2002;8:491–7.
4. Executive Department of Health and Welfare, Central Agency of Health, Business Performance Report. Available at: [http://www.nhi.gov.tw/webdata/webdata.aspx?menu=18&menu\\_id=703&WD\\_ID=941&webdata\\_id=942](http://www.nhi.gov.tw/webdata/webdata.aspx?menu=18&menu_id=703&WD_ID=941&webdata_id=942). Accessed Feb 19, 2017.
5. Yeh SH, Johnson MA, Wang ST. The changes in caregiver burden following nursing home placement. *Int J Nurs Stud* 2002;39:591–600.
6. Servello A, Camellini C, Cicerchia M, et al. Physical and psychological stress in a group of Italian caregivers: a new medical emergency? A pilot study. *Igiene e Sanita Pubblica* 2015;71:489–98.
7. Mu PF, Wang KK, Chen YC, et al. A systematic review of the experiences of adult ventilator-dependent patients. *JBI libr Syst Rev* 2010;8:344–81.
8. Im K, Belle SH, Schulz R, et al. Prevalence and outcomes of caregiving after prolonged (> or = 48 hours) mechanical ventilation in the ICU. *Chest* 2004;125:597–606.
9. Nelson JE, Kinjo K, Meier DE, et al. When critical illness becomes chronic: informational needs of patients and families. *J Crit Care* 2005;20:79–89.
10. Huang TT, Peng JM. Role adaptation of family caregivers for ventilator-dependent patients: transition from respiratory care ward to home. *J Clin Nurs* 2010;19:1686–94.
11. Hui C, Lin MC, Liu TC, et al. Mortality and readmission among ventilator-dependent patients after successful weaned discharge from a respiratory care ward. *J Form Med Assoc* 2010;109:446–55.
12. Van Pelt DC, Milbrandt EB, Qin L, et al. Informal caregiver burden among survivors of prolonged mechanical ventilation. *Am J Respir Crit Care Med* 2007;175:167–73.
13. Dybwik K, Tollali T, Nielsen EW, et al. Fighting the system: families caring for ventilator-dependent children and adults with complex health care needs at home. *BMC Health Serv Res* 2011;11:156.
14. Sevick MA, Sereika S, Matthews JT, et al. Home-based ventilator-dependent patients: measurement of the emotional aspects of home caregiving. *Heart Lung* 1994;23:269–78.

- [15] Lu L, Kao S, Chen F. Psychological traditionality, modernity, filial piety and their influences on subjective well-being: A parent-child dyadic design. *Indig Psychol Res Chin Soci* 2006;25:243–78.
- [16] Douglas SL, Daly BJ. Caregivers of long-term ventilator patients: physical and psychological outcomes. *Chest* 2003;123:1073–81.
- [17] Sharma N, Chakrabarti S, Grover S. Gender differences in caregiving among family—caregivers of people with mental illnesses. *World J Psychiatry* 2016;6:7–17.
- [18] Hickman RL, Jr, Douglas SL. Impact of chronic critical illness on the psychological outcomes of family members. *AACN Adv Crit Care* 2010;21:80–91.
- [19] Carson SS. Outcomes of prolonged mechanical ventilation. *Curr Opin Crit Care* 2006;12:405–11.
- [20] Evans R, Catapano MA, Brooks D, et al. Family caregiver perspectives on caring for ventilator-assisted individuals at home. *Can Respira J* 2012;19:373–9.
- [21] Wu YH, Tseng YH. The lived experience of family caregivers caring for ventilator-dependent patients at home. *J Long Term Care* 2009;13:169–89.
- [22] Lee LC, Lu MS, Chang WY. Comparing the effects of respiratory care ward and home care for long-term ventilator-dependent patients. *Taiwan Med J* 2002;6:514–22.
- [23] van Beusekom I, Bakhshi-Raiez F, de Keizer NF, et al. Reported burden on informal caregivers of ICU survivors: a literature review. *Crit Care* 2016;20:16.
- [24] Sorrell JM. Moving beyond caregiver burden: identifying helpful interventions for family caregivers. *J Psychoso Nurs Ment Health Serv* 2014;52:15–8.