

Original Article

Instruments Used to Measure Psychological Symptoms among Family Caregivers of Mechanically Ventilated Critically Ill Elderly Patients: A Systematic Review

Tabootwong Watchara, MNS. in Gerontological Nursing, RN

Department of Gerontological Nursing, Faculty of Nursing, Burapha University, Chonburi, Thailand

Kiwanuka Frank, MSc in Critical Care Nursing, PhDc

Department of Nursing Science, Faculty of Health Sciences, University of Eastern Finland, Kuopio, Finland

Correspondence: Watchara Tabootwong, Department of Gerontological Nursing, Faculty of Nursing, Burapha University, 169, Chonburi 20131, Thailand, E-mail: watchara.t2525@gmail.com

Abstract

Background: Family caregivers are responsible for caregiving for critically ill elderly patients with mechanical ventilation during hospitalization. Caregiving burden and severity of illness in the elderly patients may affect mental health of family caregivers.

Aims: This review sought to identify psychological symptoms and instruments used to measure psychological symptoms among family caregivers of mechanically ventilated critically ill elderly patients.

Methods: Studies from CINAHL, PsycINFO, PubMed, Scopus, and Web of Science were searched using keywords. The inclusion criteria considered the year of publication (2009-2018) and publication as a peer-reviewed journal article in English language. Seven studies related to the purposes of this review were identified for the final analysis. Findings were analyzed using content analysis.

Results: Family caregivers of critically ill elderly patients with mechanical ventilation experience psychological symptoms. These include anxiety, depression, strain, and posttraumatic stress. Instruments used to measure anxiety and depression comprised of the Hospital Anxiety and Depression Scale (HADS) as well as the Beck Depression Inventory-Revised (BDI-II). Whilst caregiver strain was measured with the Caregiver Strain Index (CSI). The Impact of Events Scale-Revised (IES-R), the Posttraumatic Symptom Scale (PTSS-10), the Trauma Screen Questionnaire (TSQ), and The Posttraumatic Stress Disorder Checklist (PCL-5) were used to measure about posttraumatic stress symptoms.

Conclusions: Family caregivers of critically ill elderly patients receiving mechanical ventilation suffer from symptoms of anxiety, depression, as well as strain and posttraumatic stress. Thus, they should often be assessed for psychological symptoms with an appropriate tool. In addition, they should receive assistance and support from healthcare professionals once they are diagnosed with psychological symptoms.

Keywords: caregivers, critically illness, elderly, family, mechanical ventilation, psychological symptoms.

Introduction

The number of critically ill elderly patients with mechanical ventilation is increasing in hospitals (Orsini et al., 2015). Among elderly receiving mechanical ventilation, 67.8% are above 65 years of age and 43.5% are above 70 years of age while the mean age of these patients is 70 years (Aggarwal et al., 2017). The main diagnoses on admission include acute respiratory failure, septic shock, and cardiac arrest (Orsini et al., 2015, Le Borgne et al., 2018). Advanced age and critical illness contribute to the bulk of factors warranting

use of mechanical ventilation (Orsini et al., 2015). Admission of critically ill elderly patients to hospital affects the family as a unit due to changes in roles and responsibilities. These changes are evident in daily routines, emotions, and social relations (Frivold et al., 2016, Kiwanuka et al., 2019). Although elderly patients are monitored and managed by physicians and nurses; family caregivers also partly care for elderly patients during hospitalization (Happ et al., 2015). They often participate in routine care and communicating with doctors and nurses (Bhalla et al., 2014). While

caring for critically ill elderly patients, family caregivers confront various challenges such as insufficient sleep, physical exhaustion, stress, depression, reduced social interaction, and increasing expenses associated with caring for elderly patients (Liu et al., 2015). Choi et al. (2016) reviewed the impact of caregiving on psychological and physical health of family caregivers in the intensive care unit (ICU). Their findings revealed psychological symptoms as depression, anxiety, and post-traumatic stress disorder were highly prevalent. Likewise, the study of Van den Born-van Zanten et al. (2016) highlighted that 21% of family caregivers had a high level of strain and posttraumatic stress symptoms related to care provision after intensive care admission. Furthermore, family caregivers of critically ill patients often experience a cascade of psychological symptoms known as Post Intensive Care Syndrome Family (PICS-F) (Kiwanuka et al., 2019).

Therefore, family caregivers' symptoms are often assessed to find out a risk of psychological symptoms using various assessment tools such as the Impact of Event Scale-Revised (IES-R) as well as the Hospital Anxiety and Depression Scale (HADS) (McAdam et al., 2012). Köse et al. (2016) used The Hospital Anxiety and Depression Scale to assess anxiety and depression in relatives of patients admitted in ICU, higher rates of anxiety and depression were revealed among family caregivers. Conclusively, family caregivers are at risk of psychological symptoms following hospitalization of elderly patients. Evidence on the psychological symptom burden is seminal in designing interventions aimed at preventing psychological symptoms among family caregivers (Van den Born-van Zanten et al., 2016). Specifically, instruments that can be used for assessing psychological symptoms among family caregivers of critically ill elderly patients with mechanical ventilation. Therefore, this systematic review was conducted to identify psychological symptoms and instruments used for measuring the psychological symptoms among family caregivers of critically ill elderly patients receiving mechanical ventilation.

Purpose of this review

The two main objectives of the review were:

- 1) To identify the psychological symptoms of family caregivers for critically ill elderly patients with mechanical ventilation.
- 2) To identify instruments used in the published literature for measuring psychological

symptom in family caregivers of critically ill elderly patients with mechanical ventilation.

Methods

This systematic review is the synthesis of quantitative data. It uses systematic methods to identify, select, and critically appraise relevant research, as well as to collect and analyze data from primary research studies (Moher et al., 2009, Oh, 2016).

Search strategy: Five electronic databases were chosen for this systematic review: CINAHL, PsycINFO, PubMed, Scopus, and Web of Science. The search terms used included psychological, mental, emotional, family, caregivers, older, elderly, aging, aged, mechanical ventilation, and critically ill patients. These terms were combined with Boolean operators. In addition, the search was performed with appropriate adjustments made to align the strategy to the requirements of each database. The inclusion criteria included; the year of publication (2009 – 2018), publication in the English language, term/ keyword (as used in the databases), and publication as a research article in a peer-reviewed scientific journal.

The process of selecting studies: We conducted this systematic review with reference to the PRISMA statement consisting of identification, screening, eligibility, and included (Moher et al., 2009):

- 1) Identification; 1,630 articles were identified from electronic databases by using the search terms which were combined by AND/ OR operators. The aim was to identify articles reporting on family caregivers of critically ill elderly patients with mechanical ventilation. Therefore, 1,501 articles based on the title were excluded because they focused on critically ill patients without family caregivers. Additionally, 20 articles involving family caregivers of critically ill patients were eliminated as well because they were found to be duplicates.
- 2) Screening; 109 articles based on the title were screened, these specifically focused on family caregivers of critically ill patients with mechanical ventilation. At this stage, 81 studies were excluded based on the following reasons; 1) studies focused on family caregivers of (a) children and adult patients with mechanical ventilation and (b) patients with chronic illness in a critical care unit, 2) studies were conducted with qualitative method and review, and 3) studies were not focused on the psychological impact of caregiving.
- 3) Eligibility; full texts articles (n = 28) were assessed for eligibility by two reviewers (WT and FK). The main outcome variables assessed included

(a) family caregivers of critically ill elderly patients as mean age of patients was 60 years or older and (b) psychological outcomes of caregiving during hospitalization. The second step, after screening with inclusion criteria at first step, Quality Assessment Tool for Quantitative Studies developed by the Effective Public Health Practice Project (EPHPP) was used to assess the quality of primary research studies (Evans et al., 2015). The EPHPP tool was designed to assess quantitative study, according to eight components (A–H): (A) selection bias; (B) study design; (C) confounders; (D) blinding; (E) data collection methods; (F) withdrawals and drop-outs; (G) intervention integrity; and (H) analyses. Components A to F were assigned a rating of strong, moderate, and weak. Components G and H required the recording of descriptive information, in line with recommendations. With both reviewers discussing the rating, we indicated the reason for the discrepancy and determined the consensus as strong (no weak ratings), moderate (one weak rating), or weak (two or more weak ratings). Included; 7 articles were considered having strong and moderate quality and related to the purpose of this systematic review, but 21 articles were excluded based on data in full-text articles because those articles were not related to the purpose of this review. The process of selecting articles for inclusion in this systematic review is shown in Figure 1.

Data analysis: The methods and results from seven quantitative studies were analyzed using content analysis to identify psychological symptom and instruments used for measuring psychological symptoms in family caregivers of mechanically ventilated critically ill elderly patients. Three steps of content analysis consisted of preparation, organizing, and reporting (Vaismoradi et al., 2013). During preparation, we read methods and results of full-text articles to obtain the sense of whole data and decide on the analysis of manifesting content. We then organized the manifesting content by opening codes, creating categories, and grouping codes under higher order headings. Finally, reporting the results were presented through narratives (Whittemore, 2005) regarding psychological symptom and instruments used for measuring psychological symptom in family caregivers who are involved in caring for critically ill elderly patients with mechanical ventilation in hospital.

Results

Study characteristics: The studies selected for inclusion in this review ($n = 7$) were published between 2009 and 2018. Two articles were from

North America, Brazil ($n = 2$), Germany (1), Netherland ($n = 1$), and Taiwan ($n = 1$). With regards to study designs, one study used, one study was descriptive, three studies were prospective in nature, two studies were cross-sectional, and one study used a longitudinal design. All studies were conducted in ICU. Majority of the family caregivers were spouses of the patients and they were female. A summary of the studies included in the final analysis of this review are shown in Table 1.

Psychological symptoms and instruments used for measuring them: Instruments for measuring psychological symptoms are shown in Table 2. Family caregivers experience psychological symptoms such as anxiety, depression, as well as strain and posttraumatic stress as follows:

1) Anxiety: family caregivers of critically ill elderly patients who had a more severe disease (Fumis et al., 2015) and receiving prolonged mechanical ventilation (Fumis and Deheinzelin, 2009) were at higher risk of anxiety (Petrinec, 2017). Anxiety was associated with two family-related factors consisting of gender and dissatisfaction with care. Females had a higher risk of anxiety compared to males (Fumis and Deheinzelin, 2009). Dissatisfaction with care expressed in form of requesting form of demanding for more frequent care and the need for information on the patient's condition were the other contributing attributes to anxiety (Fumis et al., 2015). To assess a family caregiver who was at risk of anxiety, the Hospital Anxiety and Depression Scale (HADS) was the common instrument used to assess for signs and symptoms of anxiety and depression (Petrinec, 2017, Fumis and Deheinzelin, 2009, Fumis et al., 2015).

2) Depression: various studies reported that family caregivers of critically ill elderly patients with mechanical ventilation experience depression (Rabkin et al., 2009, Fumis and Deheinzelin, 2009, Fumis et al., 2015, Petrinec, 2017). Women were more likely to have symptoms of depression. Thus, gender was associated with family caregiver depression (Fumis and Deheinzelin, 2009, Fumis et al., 2015). In addition, other correlates of family caregiver depression comprised of caregiving burden and fatigue (Rabkin et al., 2009). To measure the family caregivers' depression perception, the Beck Depression Inventory-Revised (BDI-II) was the commonest instrument used for assessing the severity of depression as minimal, mild, moderate, and severe forms (Rabkin et al., 2009). Another instrument, the HADS was also used in some studies to assess depression (Fumis and Deheinzelin, 2009, Fumis et al., 2015, Petrinec, 2017).

3) Strain and posttraumatic stress: family caregivers experience some level of strain and posttraumatic stress related to symptoms of critically ill elderly patients (Van den Born-van Zanten et al., 2016). They experience physical, psychological, social, and financial impacts of caregiving. To assess family caregiver strain, the Caregiver Strain Index (CSI) was used. The CSI was used to assess strain in the domains of employment, time management, financial, physical, and social status (Van den Born-van Zanten et al., 2016). Furthermore, family caregivers also experience posttraumatic stress disorder (PTSD). The Impact of Events Scale-Revised (IES-R) was used to assess PTSD symptoms (Chang et al., 2018). The likelihood of PTSD-related symptoms, the Trauma Screen Questionnaire (TSQ) have been used to evaluate posttraumatic stress-related complaints acquired after admission of a patient in the ICU (Van den Born-van Zanten et al., 2016). Furthermore, the Posttraumatic Symptom Scale (PTSS-10) was used to assess signs and symptoms of PTSD within a time frame of up to 6 months after transferring the elderly patients from a critical care unit to rehabilitation (Wintermann et al., 2016). The diagnosis of PTSD was ascertained with the Structured Clinical Interview for the Diagnostic and Statistical Manual of Mental Disorders, fourth edition (DSM-IV). Therefore, the Posttraumatic Stress Disorder Checklist (PCL-5) was used to measure signs and symptoms of PTSD to assist in making a diagnosis of PTSD (Petrinec, 2017).

Discussion

This systematic review described psychological symptoms and various validated instruments used for assessing psychological symptoms among family caregivers of critically ill elderly patients receiving mechanical ventilation. Findings of our review revealed that family caregivers experience anxiety, depression, as well as strain and posttraumatic stress. Indeed, other reviews assessing psychological symptoms among family members of critically ill patients in ICU have also shown that they often experience anxiety about the uncertainty of patient's prognosis. In addition, the financial consequences of admission of a family in hospital also cause significant strain to the other members of the family while providing care for their loved one during hospitalization (Kiwanuka et al., 2019).

Anxiety and depression among family caregivers could also be attributed to the response to fear as family caregivers are often afraid regarding the severity of disease among patients receiving mechanical ventilation for a long time (Fumis and Deheinzelin, 2009, Fumis et al., 2015). The present

findings seem to be consistent with other research which revealed that spouses of patients who are admitted to ICU, often experience symptoms of anxiety. Indeed, female sex was associated with higher scores than male sex was in terms of anxiety (De Oliveira and Fumis, 2018). In literature, various validated instruments are available for assessing psychological symptoms experienced by family caregivers. These instruments cover the psychological symptom assessment in general or with specific items for a certain disorder. To assess the anxiety, the HADS was used to measure anxiety and depression in family caregivers of patients. The HADS is a useful screening tool used to identify emotional distress (Brennan et al., 2010). The HADS scale consists of 14 items; seven items measure symptoms of anxiety (HADS-A) and seven items measure symptoms of depression (HADS-D). If family caregivers were at risk of anxiety, they can be assessed by using the seven items of anxiety subscale (HADS-A). Each item is scored from 0 to 3, with total scores ranging from 0 to 21. Scores of ≥ 11 are considered to indicate high risks of anxiety (Köse et al., 2016).

In addition, the findings of this review indicated that family caregivers of critically ill elderly patients receiving mechanical ventilation experience depression. Depressive symptoms were the most prevalent among informal caregivers of survivors of intensive care who were ventilated for more than 48 hours to 1 year (Haines et al., 2015). Depression symptoms were more common among the patients' spouses, followed by children. In other words, the type of relationship to the patient was associated with family caregiver's depression (Köse et al., 2016). Furthermore, patient age and severity of disease predicted depression in family members of ICU elderly patients as well (Pochard et al., 2005). With regards to instruments, the Beck Depression Inventory-Revised (BDI-II) was the common instrument used to assess the severity of depression in family caregivers of critically ill elderly patients receiving mechanical ventilation. The BDI-II was developed to correspond to DSM-IV criteria for diagnosing depressive disorders (Smarr and Keefer, 2011). The 21 items assess sign and symptoms of depression including sadness, hopelessness, irritability, guilt, and physical symptoms such as fatigue, weight loss, and lack of interest in sex (Rubin and Feeling, 2013). Furthermore, our findings also revealed that the HADS-D instrument has been used to assess the symptoms of depression using the seven items of depression subscale (HADS-D). Each item is scored on a four-point scale (0 to 3), with the total score ranging from 0 to 21. Scores of ≥ 8 are considered to indicate high risks of depression

(Köse et al., 2016). Another important finding was that family caregivers of mechanically ventilated critically ill elderly patients suffered from strain and posttraumatic stress symptoms. It seems possible that this finding is due to a feeling of being overburdened. Nonetheless, feeling overburdened was a predictor of posttraumatic stress. Caregiver strain referred to the perception of stress and fatigue caused among caregivers who provided care for their patients (Creemers et al., 2016). Most common stressors were feelings of helplessness and uncertainty (Matt et al., 2017). Caregiver strain was assessed with the Caregiver Strain Index (CSI). The scale comprised of 13 items regarding employment status, physical condition, the social status of the caregiver and the changes that a caregiver experienced in providing care for the patient (Ugur and Fadiloglu, 2010). Creemers et al. (2016) studied factors related to caregiver strain. The results revealed that the increase in caregiver strain was associated with the patients' time-dependent and disease severity.

Lastly, family caregivers suffered from posttraumatic stress symptom. Experiences of posttraumatic stress among family caregivers in this regard could be attributed to the stressful life events or traumatic events directly related to the caregiving role (Kingston et al., 2016). Instruments used for measuring posttraumatic stress symptom consisted of IES-R, TSQ, PTSS-10, and PCL-5. It is recommended that the instruments used for measuring posttraumatic stress should be in accordance with the purpose of studying as users need to: i) assess the risk of PTSD symptoms or ii) measure signs and symptoms of PTSD to qualify for the diagnosis in line with the DSM-IV (Rubin and Feeling, 2013). Our findings with regards to the instruments used for assessing PTSD are consistent with those of other studies that also highlighted that the Impact of Events Scale-Revised (IES-R), the Posttraumatic Symptom Scale (PTSS-10), and the Trauma Screen Questionnaire (TSQ) were considered to assess posttraumatic stress symptom in family caregiver of patients in the hospital. The results manifested that family caregivers experience stress and they had the symptoms of posttraumatic stress. Moreover, family caregivers often met the criteria for the diagnosis of PTSD (Chang et al., 2018, Wintermann et al., 2016, Van den Born-van Zanten et al., 2016, Petrinc, 2017).

The implications of findings to practice: The Family participants in providing care for the hospitalized elderly patients. This is important as a partnership of family caregivers and healthcare professionals to improve quality of care for

critically ill elderly patients. Albeit the former importance of caregiving, risks of psychological symptoms often occur among family caregivers. Therefore, family caregivers should be screened or assessed for psychological symptoms intermittently. Once the screening is done, if findings reveal that they are a risk of psychological disorders, attention of a psychologist and psychiatric nurses should be sought to assist and support the family appropriately.

Limitations of this review: Studies included in this study were limited to research articles written in the English language and restricted to articles retrieved from the five databases purposively selected for the review. It is possible that information from studies published elsewhere may have been missed. These may be published in other languages and databases.

Conclusion: Family Caregivers of critically ill elderly patients receiving mechanical ventilation experience various psychological disorders including anxiety, depression, strain, and posttraumatic stress. These conditions can be assessed using various standardized tools in the critical care settings. Anxiety and depression can be assessed with the HADS tool. Besides, the BDI-II tool can also be used to measure the severity of depression. Caregiver strain can be measured with the CSI. Whilst Instruments used in published literature for measuring posttraumatic stress in family caregivers include: IES-R, TSQ, PTSS-10, and PCL-5.

References

- Aggarwal, V., Singh, R., Singh, J. B., Bawa, J., Gaur, N., Kumar, S. & Nagesh, I. V. 2017. Outcomes of mechanically ventilated critically ill geriatric patients in intensive care unit. *Journal of Clinical and Diagnostic Research*, 11, OC01-OC03.
- Bhalla, A., Suri, V., Kaur, P. & Kaur, S. 2014. Involvement of the family members in caring of patients an acute care setting. *Journal of Postgraduate Medicine*, 60, 382-5.
- Brennan, C., Worrall-Davies, A., Mcmillan, D., Gilbody, S. & House, A. 2010. The Hospital Anxiety and Depression Scale: a diagnostic meta-analysis of case-finding ability. *Journal of Psychosomatic Research*, 69, 371-8.
- Chang, P. Y., Wang, H. P., Chang, T. H., Yu, J. M. & Lee, S. Y. 2018. Stress, stress-related symptoms and social support among Taiwanese primary family caregivers in intensive care units. *Intensive and Critical Care Nursing*, 49, 37-43.
- Choi, J., Donahoe, M. P. & Hoffman, L. A. 2016. Psychological and physical health in family caregivers of intensive care unit survivors: current

- knowledge and future research strategies. *Journal of Korean Academy of Nursing*, 46, 159-67.
- Creemers, H., De Moree, S., Veldink, J. H., Nollet, F., Van Den Berg, L. H. & Beelen, A. 2016. Factors related to caregiver strain in ALS: a longitudinal study. *Journal of Neurology, Neurosurgery, and Psychiatry*, 87, 775-81.
- De Oliveira, H. S. B. & Fumis, R. R. L. 2018. Sex and spouse conditions influence symptoms of anxiety, depression, and posttraumatic stress disorder in both patients admitted to intensive care units and their spouses. *Revista Brasileira de Terapia Intensiva*, 30, 35-41.
- Evans, N., Lasen, M. & Tsey, K. 2015. *A systematic review of rural development research*, New York, Springer International Publishing.
- Frivold, G., Slettebo, A. & Dale, B. 2016. Family members' lived experiences of everyday life after intensive care treatment of a loved one: a phenomenological hermeneutical study. *Journal of Clinical Nursing*, 25, 392-402.
- Fumis, R. R. & Deheinzelin, D. 2009. Family members of critically ill cancer patients: assessing the symptoms of anxiety and depression. *Intensive Care Medicine*, 35, 899-902.
- Fumis, R. R. L., Ranzani, O. T., Faria, P. P. & Schettino, G. 2015. Anxiety, depression, and satisfaction in close relatives of patients in an open visiting policy intensive care unit in Brazil. *Journal of Critical Care*, 30, 440.e1-440.e6.
- Haines, K. J., Denehy, L., Skinner, E. H., Warrillow, S. & Berney, S. 2015. Psychosocial outcomes in informal caregivers of the critically ill: a systematic review. *Critical Care Medicine*, 43, 1112-1120.
- Happ, M. B., Tate, J. A. & Davidson, J. E. 2015. Notes on family caregiving in acute and critical care. *Geriatric Nursing*, 36, 319-21.
- Kingston, C., Onwumere, J., Keen, N., Ruffell, T. & Kuipers, E. 2016. Posttraumatic stress symptoms (PTSS) in caregivers of people with psychosis and associations with caregiving experiences. *Journal of Trauma & Dissociation*, 17, 307-21.
- Kiwanuka, F., Imanipour, M., Akhavan Rad, S., Masaba, R. & Alemayehu, Y. H. 2019. Family members' experiences in adult intensive care units: a systematic review. *Scandinavian Journal of Caring Sciences*.
- Köse, I., Zincircioğlu, Ç., Öztürk, Y. K., Çakmak, M., Gildoğan, E. A., Demir, H. F., Şenoglu, N., Erbay, R. H. & Gonullu, M. 2016. Factors affecting anxiety and depression symptoms in relatives of intensive care unit patients. *Journal of Intensive Care Medicine*, 31, 611-617.
- Le Borgne, P., Maestraggi, Q., Couraud, S., Lefebvre, F., Herbrecht, J. E., Boivin, A., Michard, B., Castelain, V., Kaltenbach, G., Bilbault, P. & Schneider, F. 2018. Critically ill elderly patients (>= 90 years): clinical characteristics, outcome and financial implications. *PLoS One*, 13, e0198360.
- Liu, Y.-Y., Chen, Y.-M., Liu, J.-F., Tu, M.-L., Liu, S.-F., Fang, W.-F. & Lin, M.-C. 2015. Burdens of caregivers for patients with chronic ventilator-dependent: impact of gender differences. *Chest*, 148, 486A-486B.
- Matt, B., Schwarzkopf, D., Reinhart, K., König, C. & Hartog, C. S. 2017. Relatives' perception of stressors and psychological outcomes – results from a survey study. *Journal of Critical Care*, 39, 172-177.
- McAdam, J. L., Fontaine, D. K., White, D. B., Dracup, K. A. & Puntillo, K. A. 2012. Psychological symptoms of family members of high-risk intensive care unit patients. *American Journal of Critical Care*, 21, 386-93; quiz 394.
- Moher, D., Liberati, A., Tetzlaff, J. & Altman, D. G. 2009. Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement. *Public Library of Science Medicine*, 6, e1000097.
- Oh, E. G. 2016. Synthesizing quantitative evidence for evidence-based nursing: systematic review. *Asian Nursing Research*, 10, 89-93.
- Orsini, J., Butala, A., Salomon, S., Studer, S., Gadhia, S., Shamian, B., Prajapati, R. & Blaak, C. 2015. Prognostic factors associated with adverse outcome among critically ill elderly patients admitted to the intensive care unit. *Geriatrics & Gerontology International*, 15, 889-94.
- Petrinec, A. 2017. Post-intensive care syndrome in family decision makers of long-term acute care hospital patients. *American Journal of Critical Care*, 26, 416-422.
- Pochard, F., Darmon, M., Fassier, T., Bollaert, P. E., Cheval, C., Coloigner, M., Merouani, A., Moulront, S., Pigne, E., Pingat, J., Zahar, J. R., Schlemmer, B. & Azoulay, E. 2005. Symptoms of anxiety and depression in family members of intensive care unit patients before discharge or death. A prospective multicenter study. *Journal of Critical Care*, 20.
- Rabkin, J. G., Albert, S. M., Rowland, L. P. & Mitsumoto, H. 2009. How common is depression among ALS caregivers? A longitudinal study. *Amyotrophic Lateral Sclerosis*, 10, 448-55.
- Rubin, D. C. & Feeling, N. 2013. Measuring the severity of negative and traumatic events. *Clinical Psychological Science*, 1, 375-389.
- Smarr, K. L. & Keefer, A. L. 2011. Measures of depression and depressive symptoms: Beck Depression Inventory-II (BDI-II), Center for Epidemiologic Studies Depression Scale (CES-D), Geriatric Depression Scale (GDS), Hospital Anxiety and Depression Scale (HADS), and Patient Health Questionnaire-9 (PHQ-9). *Arthritis Care & Research*, 63 Suppl 11, S454-66.
- Ugur, O. & Fadiloglu, C. 2010. "Caregiver Strain Index" validity and reliability in Turkish society.

- Asian Pacific Journal of Cancer Prevention*, 11, 1669-75.
- Vaismoradi, M., Turunen, H. & Bondas, T. 2013. Content analysis and thematic analysis: Implications for conducting a qualitative descriptive study. *Nursing & Health Sciences*, 15, 398-405.
- Van Den Born-Van Zanten, S. A., Dongelmans, D. A., Dettling-Ihnenfeldt, D., Vink, R. & Van Der Schaaf, M. 2016. Caregiver strain and posttraumatic stress symptoms of informal caregivers of intensive care unit survivors. *Rehabilitation Psychology*, 61, 173-8.
- Whittemore, R. 2005. Combining evidence in nursing research: methods and implications. *Nursing Research*, 54, 56-62.
- Wintermann, G. B., Weidner, K., Strauss, B., Rosendahl, J. & Petrowski, K. 2016. Predictors of posttraumatic stress and quality of life in family members of chronically critically ill patients after intensive care. *Annals of Intensive Care*, 6, 69.

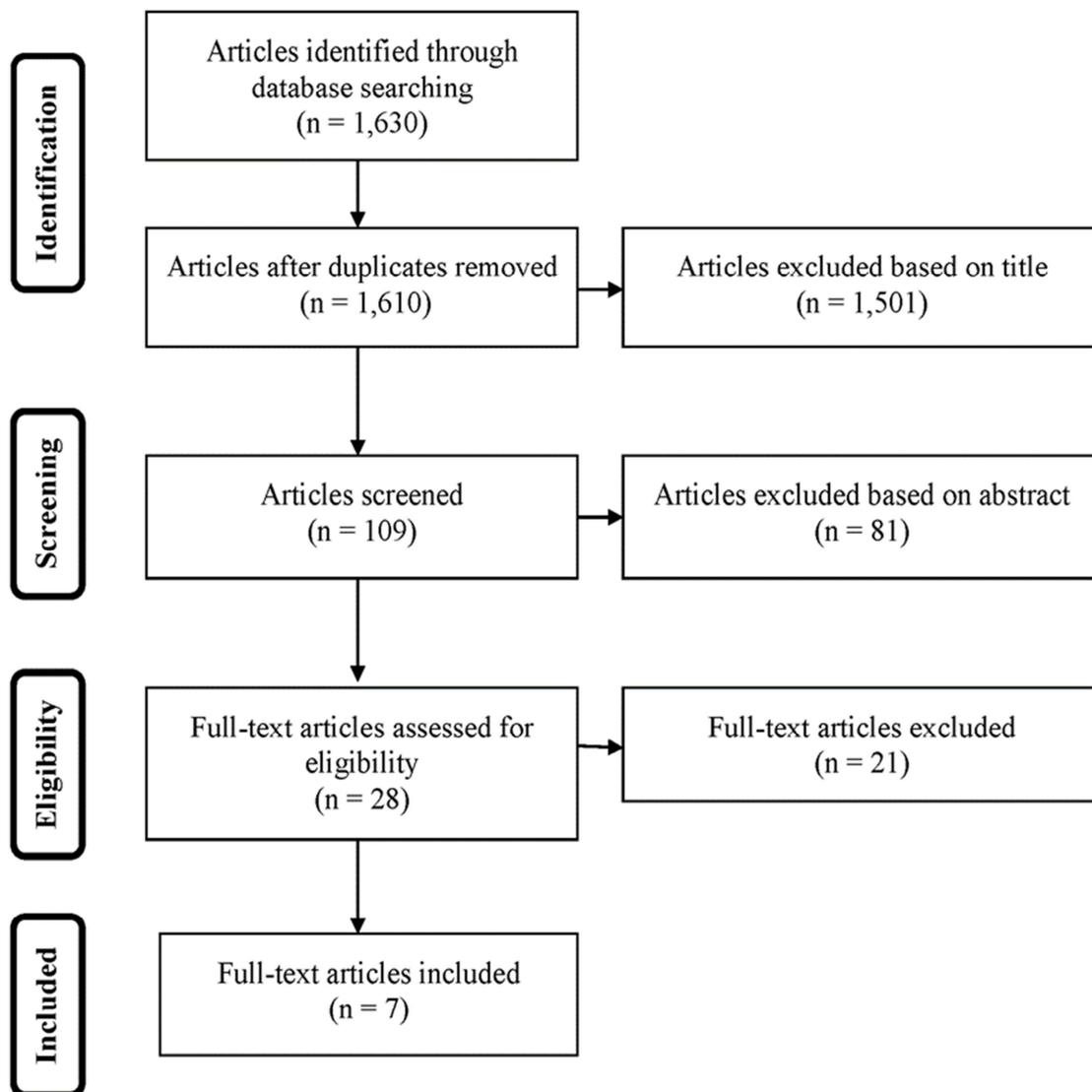


Figure 1. The process of selecting articles for inclusion in a systematic review

Table 1. Studies included in the review covering psychological symptom of family caregivers of critically ill elderly patients with mechanical ventilation (N=7)

Author, Year / Country	Purpose	Sample	Design/ Instruments	Statistical analysis	Main results
Rabkin et al., 2009 (New York, USA)	To assess the impact of personal, situational and patient characteristics on mood, and changes over time, among ALS caregivers.	80 patient-caregiver pairs	<ul style="list-style-type: none"> - Descriptive design - Demographic questionnaire - Patient Health Questionnaire (PHQ-9) - Beck Depression Inventory-Revised (BDI-II) - Manne Scales of Positive and Negative Dyad Support - Caregiver Burden and Satisfaction - The Amyotrophic Lateral Sclerosis Functional Rating Scale-Revised (ALSFRS-R) - Chalder Fatigue Scale - Folkman's Ways of Coping Scale 	<ul style="list-style-type: none"> - Categorical data were analyzed using χ^2 tests - T-tests were used for comparison of continuous variables. - Pearson correlations were used to analyze relationships between measures of distress and resilience. 	<ul style="list-style-type: none"> - 57% of patients were men. Mean age was 62 years (range 27–85 years). - The mean caregiver age was 57 years (SD=15). 74% were women. 63% were spouses or partners. 13% of caregivers had major depression and 10% had minor depression. - Correlates of caregiver depression included reliance on avoidance, perceived burden, fatigue, and feeling that the patient was critical and unappreciative.

Table 1. (Continued)

Author, Year / Country	Purpose	Sample	Design/ Instruments	Statistical analysis	Main results
Fumis and Deheinzelin, 2009 (Brazil)	To determine the prevalence and factors associated with symptoms of anxiety and depression in family members of critically ill cancer patients.	- 443 patients - 300 family members	- Prospective research - Demographic questionnaire - The Hospital Anxiety and Depression Scale (HADS)	- Data were expressed as median (interquartile range). - Continuous variables were categorized according to the median. Contingency tables for each variable and anxiety, depression or both were analyzed with Chi-Square (χ^2).	- The median age of patients was 63 (Range = 53–73) years. 52% were men. - Most of family members were women (65%), median age was 45 years (Range = 36–55), and 69% were married. - Prevalence of anxiety and depression in family members was 71% and 50.3%, respectively. - Anxiety was independently associated with one patient-related factor (prolonged mechanical ventilation) and two family-related factors (religion and gender). - Factors associated with symptoms of depression included one patient-related factor (presence of metastasis) and one family-related factor (gender).
Fumis et al., 2015	To evaluate the satisfaction and	- 1,125 patients	- Prospective research - Demographic	- Data are presented as mean \pm SD or	- The median patient age was 69 (Range = 56-80) years. 60% were

(Brazil)	symptoms of anxiety and depression in family members	- 471 family members	questionnaire - Family Needs Inventory	median. - Comparisons among groups were evaluated using	men. - Majority of family members were women (78%). 47% of the family members were spouses. Median age was 54 (Range = 45-62) years.
----------	--	----------------------	--	---	--

Table 1. (Continued)

Author, Year / Country	Purpose	Sample	Design/ Instruments	Statistical analysis	Main results
	in an open visiting intensive care unit (ICU).		- The Hospital Anxiety and Depression Scale (HADS)	Mann-Whitney U or unpaired t-test, as appropriate. - Fisher exact test or χ^2 tests were used for dichotomous variables.	- Prevalence of anxiety and depression were of 34% and 17%, respectively. - Women were more likely to have symptoms of anxiety (P= .051) and were significantly associated with symptoms of depression.
Wintermann et al., 2016 (Germany)	To investigate patient and family-related risk factors for posttraumatic stress and decreased HRQL in family members of CCI patients.	83 patient-family member dyads	- Cross-sectional research - Demographic questionnaire - The Posttraumatic Symptom Scale (PTSS-10) - The questionnaire Euro-Quality of Life (EQ-5D-3L) - The Barthel index - The Acute Stress Disorder Scale (ASDS)	- The point-biserial correlation was used for dichotomous and continuous variables. - Wilcoxon’s signed-rank test was used to compare means of outcome variables (HRQL/ PTSS) between patients and family members. - McNemar test was	- 71.1% of the family members were partners. 72.3 % were women. - Family members were significantly younger (median age 59.9) than patients (median age 61.7). - Family members were a risk of posttraumatic stress. - Factors independently associated with posttraumatic stress among family members were: time following ICU discharge and the patients’ diagnosis of PTSD.

conducted in case of dyadic nominal outcome data. - Perceived satisfaction with the relationship turned out to be a protective factor for posttraumatic stress in family members of CCI patients.

Table 1. (Continued)

Author, Year / Country	Purpose	Sample	Design/ Instruments	Statistical analysis	Main results
Van den Born-van Zanten et al., 2016 (Netherland)	To describe the level of caregiver strain and posttraumatic stress-related symptoms in relatives of ICU survivors.	94 relatives of patients admitted to the ICU	- Prospective research - Demographic questionnaire - The Caregiver Strain Index (CSI) - The Trauma Screen Questionnaire (TSQ)	- Descriptive statistics were used to describe demographics and CSI/TSQ scores. - Categorical variables are reported as proportions. - If correlation was suspected between baseline characteristics and a high CSI/TSQ score, bivariate analyses were used.	- 69 % of patients were male with an M ± SD age of 66 ± 10 years. - Most relatives were female (71%), with an M ± SD age of 57 ± 16 years, and 76% of the relatives were spouses. - Twenty-one percent of the caregivers had a CSI score of 7 or more, indicating high levels of strain. - PTSD-related symptoms were seen in 21% of the caregivers.
Petrinec, 2017	To examine indications of	30 family caregivers.	- Longitudinal research - Demographic	- Descriptive statistics were used	- The median patient age was 60.7 (Range = 32-87) years.

(Ohio, USA)	post-intensive care syndrome, coping strategies, and health-related quality of life among family	questionnaire - The Hospital Anxiety and Depression Scale (HADS) - The PCL-5 - The Brief COPE Instrument.	to assess frequencies and variability of the data. - Bivariate associations were examined by using Pearson	- Family caregivers were spouses (33%) and children (23%). - 80 % of family caregivers were female. The median age was 56.8 (Range = 40-83) years.
-------------	--	--	---	---

Table 1. (Continued)

Author, Year / Country	Purpose	Sample	Design/ Instruments	Statistical analysis	Main results
	decision makers during and after patients' long-term hospitalization.		- 36-Item Short-Form General Health Survey, version 2 (SF-36v2)	correlations and χ^2 . - Differences between groups were examined by using dependent-sample t-tests, 2-sample t-tests, and 1-way analysis of variance.	- 27% of family caregivers reported moderate to severe anxiety, and 20% reported moderate to severe depression. - 10% of family caregivers met the criteria for a provisional diagnosis of PTSD. Problems focused coping scores decreased significantly over time, and avoidant and emotion-focused coping scores remained stable. - HRQOL mental and physical summary scores at 60 days after admission were lower than scores on admission, but the difference was not significant.
Chang et al., 2018	To explore the associations	87 family caregivers	- Cross-sectional research - Demographic	- Descriptive statistics were used	- The mean age of patients was 69.1(SD=18.9) years.

(Taiwan)	between stress, sleep disturbances, fatigue severity and social support among primary family caregivers in intensive care units during the early period of	questionnaire - The Impact of Events Scale-Revised (IES-R) - The General Sleep Disturbance Scale - The Lee Fatigue Scale	to assess frequencies, percentages, means (M) and standard deviations (SD) for demographic data and all questionnaires.	- Family caregivers were female (82.1%). The mean age was 49.5 (10.7). Family caregivers were spouses (20.7%) and children (59.8). - They were distressed and experienced poor sleep quality and fatigue during the early period of ICU hospitalization. - Family caregivers have various social support needs but being updated on the patients' prognosis was at the top of the list.
----------	--	---	---	---

Table 1. (Continued)

Author, Year / Country	Purpose	Sample	Design/ Instruments	Statistical analysis	Main results
	ICU hospitalization.		- The Norbeck Social Support Questionnaire (NSSQ) - Open-ended questions were given to gain a better understanding of specific social support needs among the primary family caregivers	- Differences between groups were analyzed using t-tests and one-way ANOVA. - Pearson and Spearman's correlations were used to examine bivariate associations among the variables. - Hierarchical linear	- Perceived ICU hospitalization stress was the only significant predictor for fatigue while age along with perceived event stress were the significant predictors for sleep disturbances.

regressions were used to identify the predictors.

Table 2. Instruments used for measuring psychological symptoms

Psychological symptoms	Instrument	Reliability	Dimensions / Items	Scoring	Author, Year
Anxiety	The hospital anxiety and depression scale (HADS)	Anxiety and depression subscales had internal consistency (Cronbach’s α) of 0.68 and 0.77, respectively.	The HADS is a 14-item scale with 7 items in an anxiety subscale (HADS-A) and 7 items in a depression subscale (HADS-D). It was used to measure signs and symptoms of anxiety and depression at all time points.	<ul style="list-style-type: none"> - Each item has 4 possible responses ranging from 0 to 3. - Each of the 2 subscales can have scores ranging from 0 to 21; higher scores indicate higher levels of anxiety or depression. - A cutoff score of 11 or greater is consistent with moderate to severe indications of anxiety or depression. 	Fumis and Deheinzelin, 2009 Fumis et al., 2015 Petrinec, 2017
Depression	Beck Depression Inventory Revised (BDI-II)	Cronbach’s α = 0.93	This version of the inventory consists of 21 items. It was used to measure the family caregivers’ depression perception.	<ul style="list-style-type: none"> - Each item is scored on a scale of 0 to 3. Scores range is 0 to 63. - Depression severity: 0-13 = minimal, 14-19 = mild, 20-28 = moderate, 29-63 = severe 	Rabkin et al., 2009
Posttraumatic Stress	The Posttraumatic Symptom Scale	Cronbach’s α = 0.82	The questionnaire consists of 10 items to measure signs and symptoms of PTSD.	<ul style="list-style-type: none"> - Items are rated on a seven-point Likert scale (1 = never, 7 = always). - The total score is received by summing up the scores of all items 	Wintermann et al., 2016

(PTSS-10)

(range 10–70).

- A score of more than 35 points is considered as adequate cutoff for clinically relevant PTSD.

Table 2. (Continued)

Psychological symptoms	Instrument	Reliability	Dimensions / Items	Scoring	Author, Year
	The Trauma Screen Questionnaire (TSQ)	The overall efficiency of around 80%	It contains 10 questions to evaluate posttraumatic stress-related complaints acquired after the intensive care admission of their relative.	- Each item is answered with a binary yes or no response. - A total score higher than 5 indicates the likelihood of PTSD-related symptoms.	Van den Born-van Zanten et al., 2016
	The Posttraumatic Stress Disorder Checklist (PCL-5)	Cronbach’s $\alpha = 0.94$	The PCL-5 is a 20-item self-report measure to assess signs and symptoms of PTSD.	- Each item has 5 possible responses ranging from 0 (not at all) to 4 (extremely). - Scores range is 0-80. A total score of 33 or higher suggests the patient needs further assessment to confirm a diagnosis of PTSD.	Petrinec, 2017
	The Impact of Events Scale-Revised (IES-R)	Cronbach’s $\alpha = 0.93$	It is a 22-items to measure the caregivers’ stress perception in three subscales: intrusion, avoidance, and hyperarousal.	- Items are rated on a five-point Likert scale (0 = Not at all, 4 = Extremely). A total score greater than 33 indicates a significant risk of PTSD symptoms.	Chang et al., 2018

Strain	Caregiver Strain Index (CSI)	Cronbach's $\alpha = 0.86$	It is 13 questions tool that measures strain related to care provision. It was used to assess strain in the domains of employment, time management, and financial, physical, and social status.	Each item is answered with a binary yes or no response. A score of 7 or more indicates high levels of strain on the caregiver. A total score of 11–13 indicates severe strain.	Van den Born-van Zanten et al., 2016
--------	------------------------------	----------------------------	---	--	--------------------------------------
