

Psychological and Physical Health in Family Caregivers of Intensive Care Unit Survivors: Current Knowledge and Future Research Strategies

Choi, JiYeon¹ · Donahoe, Michael P.² · Hoffman, Leslie A.³

¹Department of Acute & Tertiary Care, School of Nursing, University of Pittsburgh, Pittsburgh, Pennsylvania

²Division of Pulmonary, Allergy & Critical Care Medicine, Department of Medicine, University of Pittsburgh School of Medicine, Pittsburgh, Pennsylvania

³Department of Acute & Tertiary Care, School of Nursing & Clinical and Translational Science Institute, University of Pittsburgh, Pittsburgh, Pennsylvania, USA

Purpose: This article provides an overview of current knowledge on the impact of caregiving on the psychological and physical health of family caregivers of intensive care unit (ICU) survivors and suggestions for future research. **Methods:** Review of selected papers published in English between January 2000 and October 2015 reporting psychological and physical health outcomes in family caregivers of ICU survivors. **Results:** In family caregivers of ICU survivors followed up to five years after patients' discharge from an ICU, psychological symptoms, manifested as depression, anxiety and post-traumatic stress disorder, were highly prevalent. Poor self-care, sleep disturbances and fatigue were identified as common physical health problems in family caregivers. Studies to date are mainly descriptive; few interventions have targeted family caregivers. Further, studies that elicit unique needs of families from diverse cultures are lacking. **Conclusion:** Studies to date have described the impact of caregiving on the psychological and physical health in family caregivers of ICU survivors. Few studies have tested interventions to support unique needs in this population. Therefore, evidence for best strategies is lacking. Future research is needed to identify ICU caregivers at greatest risk for distress, time points to target interventions with maximal efficacy, needs of those from diverse cultures and test interventions to mitigate family caregivers' burden.

Key words: Intensive care unit; Caregivers; Family

INTRODUCTION

An extensive literature has described the challenges faced by family caregivers of persons with chronic illness, including several meta-analyses [1-7]. However, comparatively less is known about family caregivers of patients who survive critical illness [8]. Advances in therapeutics have decreased mortality during the acute phase of critical illness, and created a new population of

patients who are "chronically critically ill," a term used to define ICU survivors who experience physical and/or psychological deficits that persist for months or years [9]. Due to technological advances, improved survival and a growing older adult population with multiple comorbid conditions, the number of patients who experience a complicated recovery following critical illness is expected to rise sharply [10]. Because of the cost constraints in our health care systems that limit post-ICU care expenditures

Address reprint requests to : Choi, JiYeon

University of Pittsburgh School of Nursing, 336 Victoria Building 3500 Victoria street, Pittsburgh, Pennsylvania 15261, USA
Tel: +1-412-383-7746 Fax: +1-412-383-7227 E-mail: jic11@pitt.edu

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[11], family caregivers are likely to assume more responsibility in taking care of their critically ill family member.

Family caregivers of ICU survivors are at high risk for adverse physical and psychological outcomes because recovery from critical illness can be lengthy and highly complicated. ICU survivors face numerous challenges as they attempt to recover their pre-admission health status [12]. Recovery is often prolonged, arduous and highly unpredictable [13,14]. Challenges from negative functional, neurocognitive and psychological sequelae in ICU survivors can last for months or years [15]. Most patients require substantial assistance from family members who provide daily care and support. For example, in a prospective cohort study of 817 ICU patients who required mechanical ventilation for 48 hours or longer, the majority (75%) required caregiver assistance two months after the onset of mechanical ventilation and over half (57%) who survived to 12 months continued to require caregiver assistance [16].

The scope of critical care, once narrowly focused on survival, has expanded to include initiatives to promote recovery. This new focus has, in turn, directed more attention on family caregivers. Family caregivers are integral care partners across patients' trajectories of critical illness and recovery. Therefore, understanding challenges they face and ways to better enable them to function in this role is an important element of family-centered critical care.

In this paper, we present: (1) an overview of current evidence of psychological and physical sequelae in family caregivers from the time of patients' admission to the ICU to the recovery after discharge from the ICU, and (2) summarize findings from studies testing interventions targeted to support ICU family caregivers at various stages of critical illness. Current challenges and new opportunities for research will be also discussed.

1. Psychological Outcomes

During a patient's ICU admission, family caregivers experience stress from a variety of sources, including the onset of critical illness, ICU environment, and competing demands between their presence in the ICU and personal responsibilities [17]. Because limited cognitive capacity is typical in patients during their ICU admission, family caregivers are often expected to function as a

surrogate decision maker. Family caregivers may have support from religious or spiritual resources or limited resources for support. Regardless of the extent of support available, the majority of caregivers are at high risk for psychological distress.

In the acute phase of critical illness, depressive symptoms and anxiety are the most commonly manifested psychological symptoms in family caregivers. Interviewing family caregivers in the early phase of ICU admission is challenging and thus, assessment of psychological symptoms of family caregivers during this phase has only been done in a few studies [18–22]. From the available evidence, the prevalence of both depressive symptoms and anxiety are high. In a study conducted in multiple ICUs in France, depressive symptoms and anxiety were assessed in 920 family caregivers 3–5 days after the patients' ICU admission [21]. In this study, the overall prevalence of anxiety and depressive symptoms was 69% and 34%, respectively [21]. In a study conducted in the United States, McAdam et al. [20] identified psychological symptoms in 72 family caregivers of ICU patients who were at high risk of dying (Acute Physiology and Chronic Health Evaluation II scores >20). They reported borderline symptoms of anxiety and depression in 80% and 70% of caregivers, respectively. Characteristics of family caregivers associated with a higher risk of depression and anxiety in both studies were being a woman, spouse and ethnic or cultural minority [20,21].

Often family caregivers participate in end-of-life decision-making, a consequence that can have long-term psychological complications. Siegel et al. [23] interviewed 41 family caregivers who assumed the role of primary surrogate decision maker when their loved one died in the ICU. At 3–12 months after the patient's death, one third of participants met Diagnostic and Statistical Manual of Mental disorders, Fourth edition (DSM–IV) criteria for one of the following psychiatric conditions: major depressive disorder, generalized anxiety disorder, panic disorder, or complicated grief disorders [23].

Negative psychological outcomes are not limited to caregivers who experience a patient's death in the ICU. In fact, negative psychological responses often continue following discharge [19,22,24]. Becoming an ICU survivor opens the door to a new phase of prolonged and unpredictable experiences [14]. Psychological distress may continue or be further amplified following ICU discharge [19,24–29]. In studies in which depressive symp-

toms at 2 months post-ICU discharge were measured, 34~61% of participants reported scores that indicated a clinically significant risk for depression [18,19,22,28]. In a prospective cohort study that followed 169 family caregivers, Van Pelt et al. [19] reported that 23% of caregivers had clinically significant depressive symptoms 12 months after the onset of ICU admission, comparable to the rate reported in caregivers of persons with dementia [19,30].

Symptoms of post-traumatic stress disorder (PTSD), another outcome of concern, have been reported in 35~50% of family caregivers [31–34]. For the first 6 months after patients' ICU discharge or death, symptoms of PTSD have been reported to be problematic in more than one third of family members [31,32,34]. Risk of PTSD is high if family members experienced a patient's death in the ICU or participated in end-of-life decision-making as a surrogate decision maker [35,36]. In a longitudinal study by Anderson et al. [32] that followed family members of ICU survivors who experienced the death of a patient either during ICU admission or after ICU discharge, prevalence of PTSD was the same regardless of death experience. It is unclear how symptoms of PTSD persist or change over time following ICU discharge or how they influence the physical and mental health of family caregivers. However, limited evidence suggests the impact of critical illness on family caregivers can last up to several years. Herridge et al. [15] reported that psychological distress was still present in 27% of caregivers of acute respiratory distress syndrome survivors 5 years following the patients' discharge from the ICU.

2. Physical Health Outcomes

In studies on caregivers of persons living with cancer or Alzheimer's disease, it has been reported that long-term caregiving can adversely affect caregivers' physical health [5]. In contrast, there are relatively few studies that included investigation of physical health issues in family caregivers of ICU patients who have been characterized as chronically critically ill.

During ICU admission, family caregivers have difficulty paying attention to their own health versus that of their critically ill family member. Choi et al. [37] reported that health risk behaviors during the acute phase of critical illness were worse than behav-

iors reported by family caregivers of community-dwelling older adults with disabilities [38]. In their study, 50 family caregivers completed the 11-item Caregiver Health Behavior Instrument [39] at a time when patients were on mechanical ventilation for an extended period (12 ± 8 days) following ICU admission [37]. The majority (94%) reported one or more health risk behaviors [37]. The most commonly reported behaviors were having inadequate rest (70%), inadequate exercise (76%) and skipping meals (62%). In addition, caregivers reported difficulty managing their own health issues, e.g., difficulty taking medications (22%) and scheduling (28%) or keeping (22%) doctor appointments [37].

Impaired sleep and fatigue are other prevalent, yet under investigated, health risks in family caregivers. Several studies have described problem of poor sleep in family caregivers. In a cross-sectional study by Day et al. [40], 94 family caregivers were surveyed at 4.6 ± 7.6 days after the patients' ICU admission. Almost all (94%) recalled having a normal sleep and wake cycle prior to the patients' ICU admission [40]. However, following the patients' ICU admission, only 42% reported having a normal sleep and wake cycle [40]. Difficulty in sleep was reported by 66% and 44% rated the sleep quality as "poor" or "very poor" [40]. Psychological distress due to anxiety, tension and fearfulness were the most common reasons for poor sleep [40]. Verceles et al. [41] conducted one of the few studies in which daytime sleepiness and its impact on daytime functioning was evaluated for 225 family caregivers during the patients' ICU admission. In their results, 50% of participants reported scores on the Epworth Sleepiness Scale indicating excessive daytime sleepiness (≥ 10), a typical symptom in insomnia, and 62% reported impairment of daily activities due to sleepiness [41]. Choi et al. [42] longitudinally examined fatigue in a sample of 47 family caregivers of ICU survivors for 4 months post-ICU discharge using the Short-Form 36 Health Survey (SF-36) Vitality subscale. Using a SF-36 Vitality score of equal or less than 45 as a cut off, 45~53% of participants reported significant fatigue across the study period [42]. In this study, self-reported fatigue symptoms were associated with greater depressive symptoms, caregiving burden and poor sleep quality [42]. Data trends suggested an association between worse fatigue in family caregivers and greater symptom burden in ICU survivors [42]. There were also worsening trends of fatigue in family caregivers when the patients' post-ICU discharge

course involved extended institutional care, such as transfer to a long-term acute care or skilled nursing facility [42].

Several longitudinal studies provide additional insight into physical health concerns in family caregivers of ICU survivors after patients' discharge from an ICU. Swoboda and Lipsett [29] conducted a longitudinal study that examined health care use in 128 family caregivers of surgical ICU patients from the patients' ICU admission to 12 months after their ICU discharge. They found that 11~28% of caregivers reported becoming ill during the 12 month follow-up period [29]. Data trends showed an increase in the proportion of caregivers reporting delay in seeking medical care for their own health needs over the follow-up period (from 7.4% during ICU admission to 19.2% at 12 months post-ICU

discharge) [29]. Cameron et al. [25] conducted a cross sectional survey in 47 family caregivers of ICU survivors at 23±12 months (range 6~53 month) following patients' ICU discharge. In their report, mean scores for all domains of the SF-36 were lower than those of the general population indicating negative impact on overall physical and mental health of family caregivers after long-term caregiving [25].

3. Interventions: Did they Work?

Interventions in the field of ICU survivorship are in their infancy [43]. Previous intervention studies that included evaluation of caregiver outcomes are summarized in Table 1. Two randomized

Table 1. Studies Testing Interventions in Family Caregivers of ICU Patients

Author, Year (yr)	Design Sample	Intervention	Caregiver outcome variables (Measures) Measurement time points	Results on caregiver outcomes
Jones et al. (2004) [34]	RCT N=104 Intervention, n=58 Control, n=46	ICU survivors Self-help rehabilitation manual including nutrition, exercise, home care and relaxation and coping strategies, and (2) biweekly phone calls for 6 weeks Caregivers were encouraged to use the following contents in the self-help manual: relaxation and coping with stress	Anxiety (HAD anxiety) Depressive symptoms (HAD depression) PTSD related symptoms (IES) 2 and 6 months post-ICU discharge	No significant difference in anxiety, depressive symptoms and PTSD related symptoms at 2 and 6 months between intervention and control group
Douglas et al. (2005) [44]	RCT N=290 Intervention, n=211 Control, n=79	ICU survivors Disease management program: Emotional support and instrumental support (discussion, referrals and reassurance) Individualized case management (care coordination, education and communication) services from the advanced practice nurse for 8 weeks post-ICU discharge	Caregiving burden (CRA) Physical health status (SF-8 Physical health) Depressive symptoms (CES-D) ICU discharge and 2 months post-ICU discharge	No significant differences in caregiving burden, depressive symptoms and physical health
Jones et al. (2012) [46]	RCT N=30 Intervention, n=15 Control, n=15	ICU survivors ICU diary is written by the ICU staff during ICU stay following a standardized guideline Some family members are invited to contribute if they felt they could Distribution of ICU diary occurs between 1-2 months post-ICU discharge (Intervention) or after completion of 3 months follow-up (Controls) Diary is kept during ICU stay	PTSD related symptoms (PTSS-14) 1 and 3 months post-ICU discharge	Caregivers of the patients in intervention group had significantly lower levels of PTSD related symptoms at 3 months post-ICU discharge
Cox et al. (2014) [47]	A non-randomized single group pre- and post- test design N=13 (11 ICU survivors and 2 family caregivers)	ICU survivors and family caregivers Telephone based mindfulness training Begins within 2 weeks post-home discharge and complete approximately 6 weeks after intervention initiation (6 weekly sessions)	Feasibility and acceptability Anxiety (HAD anxiety) Depressive symptoms (HAD depression) PTSD symptoms (PTSS) Coping skills (Brief COPE) Mindfulness (Facet Mindfulness Questionnaire) Quality of life (EQ-5D) Within 1 weeks post-completion of the intervention	In two caregiver participants, one showed trends of decrease in depressive symptoms, anxiety, and PTSD symptoms after the intervention Small sample size and study design limit the results

RCT, Randomized Controlled Trial; ICU, Intensive Care Unit; HAD, Hospital Anxiety Depression; IES, Impact of Event Scale; SF-8, Short Form 8 item health survey; CRA, Caregiver Reaction Assessment; CES-D, Center for Epidemiology Study Depression subscale; PTSD, Post Traumatic Stress Disorder; PTSS, Post-Traumatic Stress Symptoms; EQ-5D, Euro Quality of Life 5 dimension scale.

controlled trials tested supportive and educational interventions that mainly targeted ICU survivors and included family caregivers as a partner. Neither of them resulted in a significant decrease in caregivers' psychological outcomes [34,44]. Jones et al. [45] conducted a RCT that mainly targeted ICU survivors. In this study, 312 ICU survivors received diaries that were completed by ICU clinical staff. Contents of the diaries were related to daily events and patient progress during the ICU stay. Family caregivers were asked to contribute to the diaries if they wished [45]. Family caregivers in the intervention group reported a significant decrease in PTSD symptoms compared to family members in the control group [46]. However, the sample of family caregivers who participated in the intervention ($n=15$) or control group ($n=15$) was small. Cox et al. [47] conducted a telephone-based mindfulness training program, one of the few interventions that engaged family caregivers of ICU survivors. Positive trends were reported in psychological outcomes (i.e., depressive symptoms, anxiety and PTSD) and mindfulness in a combined sample of 11 ICU survivors and 2 family caregivers. While feasibility of conducting a telephone based psychological intervention in this population seems promising, it is difficult to suggest benefits specific to family caregivers because of the small sample size ($n=2$) [47].

4. Suggestions for Future Research

Clinicians and researchers in the field of critical care have long been aware that family caregivers are crucial care partners. Family caregivers can experience a high level of stress during their loved one's ICU admission and afterward. It is obvious that the field needs more high quality research to identify ways to best support this vulnerable family caregiver population. Despite such awareness, interventions to support family caregivers of critically ill patients at various stages of the illness and recovery continuum are lacking. It is also important to explore differences relating to ethnicity, culture and geographic regions considering potential variability in values, preferences, and support available from private and governmental sources.

Why has this field moved so slowly compared to research on family caregivers of patients with other chronic conditions, for example cancer or dementia? Numerous challenges exist in conducting research at various stages of critical illness. First, het-

erogeneity in illness and care settings creates challenges. Many factors can influence outcomes, e.g., primary diagnosis, need for mechanical ventilation, ICU length of stay. Also, ICU structure and resources may vary. This heterogeneity can create variable stressors. Second, high attrition rates are inevitable due to the high mortality of ICU survivors, up to 40% in one year [16]. This creates a challenge when attempting to conduct a longitudinal study. Withdrawal and lost contact are frequent due to competing demands of study enrollment, care provision, and transitions between different care settings [14]. Lastly, family caregivers face complex care demands. The majority of ICU survivors are diagnosed with multiple comorbid conditions that require caregiver assistance. Family caregivers often care for several individuals. In addition, many caregivers themselves are elders living with chronic health conditions. Considering all of the above factors, these challenges need to be carefully addressed when designing studies to test interventions to provide greater support to family caregivers. Suggestions for future research include the following:

- 1) Well-designed prospective descriptive studies are necessary to delineate stress response trajectories in ICU caregivers in different health care delivery systems. To date, a number of studies have highlighted the impact of critical illness on the psychological and physical health of family caregivers of ICU survivors, but few studies have clarified variability in these outcomes over time or in diverging care situations. As an example, longitudinal investigations using mixed-methods may provide data vital to guide designing future interventions to improve caregivers' health. Using a mixed-methods approach, quantitative data could be used to identify ICU caregivers at greatest risk for distress and time points in the care trajectory to target interventions with maximal efficiency and efficacy. Qualitative data can be used to identify caregivers needs and preferences (e.g., enlisting support from secondary caregivers, accessing community resources and/or problem solving) and guide core content and delivery strategies for new interventions. Notably, none of the interventions tested to date demonstrated a significant decrease in psychological distress [34,44]. One of the keys to overcoming barriers found in the previous trials might be clarifying individual factors determining caregiver stress trajectories and enhancing the quality of evidence underpinning specific target groups, timing,

content and delivery strategies of the interventions.

2) Strategies are needed to increase support to family caregivers at the early stage of critical illness. Grounded from the model, Facilitated Sense Making, Davidson and colleagues [48] designed a family support program that aims to help family members become familiar with the ICU environment and roles in the ICU and ultimately reduce adverse psychological outcomes following the ICU experience. The recommended activities entail minimal time (20 minutes on average) interacting with family caregivers to provide a structured orientation to the environment and their role and introduce available resources. The intervention is low-tech and can be effectively delivered by any level of personnel after training (e.g., hospital volunteers). This or similar approaches offer a low-cost means to expand family caregiver support.

3) ICU diaries may benefit family caregivers and ICU survivors. Describing their observation and reaction in diaries during ICU stay may be a therapeutic activity to help family caregivers keep their concerns in perspective and better manage their stress. When shared with ICU survivors, information in the diaries helped to clarify events and minimize altered recall. A low cost, easy to implement strategy, this approach needs further testing in different settings and longitudinal assessment to identify benefits.

4) Telephone-based mindfulness interventions are a potential means to support family caregivers. Interventions using this strategy have been successful in other settings and, because of their focus on relieving stress, may provide support for ICU survivors and their caregivers. In previous studies that included caregivers [34,44], skills and information were focused on assisting long-term recovery of patients rather than supporting family caregivers. The telephone-based mindfulness intervention introduced by Cox et al. [47] has the potential to be expanded to a larger scale using various modalities (e.g., mobile phone) across care settings (e.g., family waiting areas in ICU or long-term care facilities).

5) Post-intensive care syndrome family (PICS-F) has been proposed as a new term to describe psychological conditions that can result from the need to provide care for ICU survivors, including

symptoms of depression, anxiety, post-traumatic stress disorder (PTSD), and complicated grief [49]. While proposing PICS-F is a meaningful step, it neglects consideration of the acute phase of critical illness (i.e., early period of ICU admission) when stressful experiences begin. The impact of critical illness on family caregivers' physical health is also not considered, although it is an equally important area. Current evidence in family caregivers of other chronic conditions (e.g., cancer, dementia) affirms that behavioral consequences, such as inadequate self-care, are common in caregivers and may be linked to a decline in overall physical health [39,50].

5. Clinical Implications

We also suggest several clinical implications for ICU nurses to promote support for psychological and physical needs in family caregivers. In the ICU, nurses can provide psychological support by insuring the family receives daily care updates, encouraging family meetings to discuss the patient's illness and prognosis, and engaging family members in discussions about concerns and personal needs. Family members may be hesitant to express concerns or acknowledge their lack of understanding of the ICU environment and care regimen. Nurses are in a unique position to provide insight and support that can be invaluable to family caregivers. Nurses can also encourage family caregivers to take time to attend to their own physical health needs during the acute phase of the ICU experience. Caregivers often benefit from being informed of the benefit from taking care of their physical health. Further, nurses can discuss the importance of being attentive to family caregivers' own physical and mental health during the post-ICU discharge phase by eliciting the help of other family members or other sources of respite care.

CONCLUSION

Family caregivers of ICU survivors are a vulnerable, but under supported population. Data from studies to date have highlighted problems and challenges across the stages of illness and recovery, but interventions to support unique needs in this family caregiver population are lacking. This focused review supports the importance of conducting further comprehensive descriptive

studies, as well as testing interventions to provide needed support. Studies that elicit needs in different cultural settings are particularly lacking.

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