




Caregiver burden and emotional wellbeing in informal caregivers to ICU survivors—A prospective cohort study

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Abstract

Background: Informal caregivers to intensive care unit (ICU) survivors may develop post-intensive care syndrome family (PICS-F), including depression, anxiety and post-traumatic stress (PTS). Our primary aim was to investigate associations between caregiver burden in informal caregivers cohabiting with ICU survivors and patients' physical and psychological outcomes.

Methods: A prospective, multicentre cohort study in four ICUs in Sweden. Adults cohabiting with ICU patients included in a previous study were eligible for inclusion. Three months post-ICU, informal caregivers received questionnaires assessing caregiver burden, health-related quality of life (HRQL) and symptoms of depression, anxiety and PTS. In parallel, patients reported their three-month physical and psychological status via validated questionnaires. The primary outcome of this study was to compare caregiver burden in informal caregivers to patients with and without adverse physical and psychological outcomes 3 months post-ICU. Secondary outcomes were correlations between caregiver burden and informal caregivers' mental HRQL.

Results: Among 62 included informal caregivers, 55 (89%) responded to the follow-up questionnaires. Caregiver burden was higher among informal caregivers to patients with an adverse outcome, compared to informal caregivers to patients without an adverse outcome, caregiver burden scale score mean (\pm standard deviation) 52 (11) and 41 (13) respectively ($p = 0.003$). There was strong negative correlation between caregiver burden and informal caregivers' mental HRQL ($r_s -0.74$, $p < 0.001$).

Conclusion: Informal caregivers to ICU survivors with adverse physical or psychological outcome experience a higher caregiver burden. A higher caregiver burden correlates with worse caregiver mental HRQL. ICU follow-up programs should consider screening and follow-up of informal caregivers for mental health problems.

KEYWORDS

anxiety, caregiver burden, critical care, depression, informal caregivers, intensive care unit, PICS, PICS-F, posttraumatic stress, psychological

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Editorial Comment

Family and relatives to ICU patients are a risk group for developing post-traumatic stress symptoms, which is sometimes not well recognized. For individuals related to ICU survivors such symptoms may come at a time-point when the former ICU patient starts to recover. Better knowledge in this field is a prerequisite to offer a better support.

1 | BACKGROUND

Family members to patients surviving intensive care unit (ICU) stay are often assigned a great responsibility as informal caregivers for the continued care and rehabilitation of the patient after hospital discharge.¹ An informal caregiver is defined as a family member or friend providing unpaid care for the ICU survivor.² In the aftermath of intensive care, as many as 64% of ICU survivors suffer from Post-Intensive Care Syndrome (PICS), the triad of mental, physical and cognitive problems.^{3,4} Informal caregivers to ICU survivors have been found to experience mental health problems and reduced mental health-related quality of life (HRQL) in the months after their family member's ICU stay.⁵ The prevalence of these problems varies greatly across studies,⁶ but as many as 25–30% of informal caregivers to ICU survivors suffer from symptoms of depression,^{7,8} 20–40% from anxiety,^{9,10} and 30% from symptoms of post-traumatic stress (PTS).^{9,10} These problems in informal caregivers have been named Post-Intensive Care Syndrome-Family (PICS-F).⁴ Suffering from PICS-F, while also caring for an ICU survivor may impede an informal caregiver's ability to work or participate in other regular activities, imposing both an economical as well as emotional burden. Informal caregivers' mental health status might affect the ability to support the ICU survivor in his/her recovery.

Few studies have assessed the impact of patient recovery on the experienced burden for cohabiting informal caregivers, and to what extent caregiver burden affects informal caregivers' psychological state and HRQL. Living with and caring for an ICU survivor might be particularly burdening in the face of incomplete physical or psychological recovery. The primary aim with this study was to investigate the association between caregiver burden and an incomplete physical or psychological patient recovery three months after ICU stay. We also aimed to evaluate the prevalence of psychological symptoms among informal caregivers and association between caregiver burden and informal caregivers' psychological symptoms and mental HRQL.

2 | METHODS

The current study was an a priori planned sub study within a larger research project, in which ICU survivors reported physical and psychological outcomes 3 months post-ICU.^{11,12} Four centres in tertiary care hospitals in Sweden took part in the current study. Adult cohabitants to ICU patients included in participating hospitals were approached and asked about study participation when visiting the ICU at times when research staff was available. In brief, patients ≥ 18 years of age and with ICU length of stay (LOS) ≥ 12 h were eligible for inclusion in the larger study during January to April 2016. Study participants

were excluded if they could not understand written Swedish. Patients were followed up with validated questionnaires regarding their physical and psychological state three months after the ICU stay.

The Stockholm ethical review board approved the current study (registration number 2015/1799-31), which was performed in accordance with the 1964 Declaration of Helsinki and its later amendments. All study participants (hereafter referred to as informal caregivers) and patients gave informed consent. The study was registered at clinicaltrials.gov, NCT02712541.

2.1 | Data collection in the ICU

Patient data collection in the ICU consisted of age, sex, admission diagnosis (medical, surgical or trauma), severity of disease (APACHE II score), occurrence and duration of invasive mechanical ventilation and ICU length of stay (LOS). Information regarding patients' pre-ICU physical function (assessed with the Barthel Index (BI)) was collected by asking the patients or the informal caregivers. A chart review was performed when this information was difficult to obtain.

Data on informal caregivers' age, sex and relation to the patient were collected. Informal caregivers were also asked to compile the RAND-36 at inclusion, with their status two weeks prior to hospitalization of the patient in mind, as a proxy for baseline HRQL. The RAND-36 is a validated 36-item questionnaire assessing eight domains regarding HRQL. The domains can be divided into two component scores, the mental health component score (MCS) and the physical health component score. A higher score indicates better HRQL.¹³

2.2 | Data collection at follow-up

Three months after ICU discharge questionnaires were sent by postal mail to patients and their informal caregivers in parallel.

Patients received questionnaires assessing physical and psychological problems. Physical problems were assessed with the Barthel Index (BI), a 10-item questionnaire with a maximum score of 100, assessing the independency in performing activities of daily living.¹⁴ Depressive symptoms and anxiety were assessed with the Hospital Anxiety and Depression Scale (HADS) consisting of 14 validated questions assessing depression (7 items) and anxiety (7 items). Each question generates a score from 0 to 3, a higher score indicating more severe problems.¹⁵ Symptoms of post-traumatic stress (PTS) were assessed with the Post-traumatic Stress Syndrome 14-Questions Inventory (PTSS-14) part B, a 14-item validated questionnaire. Each item generates a score from 1 (never) to 7 (always).¹⁶

Informal caregivers received the Caregiver Burden Scale (CBS), a 22-item questionnaire assessing the perceived caregiver burden among people caring for family members with need for assistance due to mental or physical limitations. The scale has been used to evaluate caregiver burden among informal caregivers to patients with different medical conditions.¹⁷ Each item generates a score between 1 and 4, a higher score indicating a higher degree of burden.¹⁸ Questions cover practical as well as emotional issues, such as general strain, isolation, disappointment, emotional involvement and environment. They also received the RAND-36, the HADS, and PTSS-14.

Two weeks after the questionnaires were posted, non-responders received a reminder phone call. A new set of questionnaires was posted if participants did not respond to the call.

2.3 | Definition of patient outcomes

Patients were considered to have an adverse outcome if they scored above the pre-defined cut-off in either the physical or psychological follow-up questionnaires. A ≥ 10 point reduction in the BI total score compared to baseline was considered an adverse physical outcome,¹¹ and is close to the suggested minimal clinically important difference for the BI.¹⁹ In the HADS questionnaire, a subscale score ≥ 11 was used to define substantial symptoms of depression or anxiety.¹⁵ In the PTSS-14 part B a score > 45 was used to define substantial symptoms of posttraumatic stress disorder.¹⁶ A score above cut-off in any of the two HADS subscales, and/or the PTSS-14 part B was considered an adverse psychological outcome.¹²

2.4 | Caregiver outcomes

The primary outcome was caregiver burden, assessed with the CBS, in relation to adverse psychological or physical patient outcome. Secondary outcomes were prevalence of symptoms of anxiety, depression or posttraumatic stress, measured with the HADS and the PTSS-14 among informal caregivers and associations between caregiver burden and informal caregivers' psychological symptoms and mental HRQL (measured with RAND-36). Further, informal caregivers were asked to state the number of days they had refrained from any planned activities, and the number of sick-days due to taking care of their cohabitant ICU survivor. They were also asked an open-ended question regarding additional measures they believed could have been helpful in order to contribute to the patient's full recovery.

2.5 | Statistical methods

2.5.1 | Sample size estimation

An estimated difference of 10 points in CBS mean scores between informal caregivers to patients with an adverse outcome (CBS score 50, standard deviation (SD) ± 15) and informal caregivers to patients

without an adverse outcome (CBS score 40, SD ± 15) would render a sample size of 70. With an estimated loss to follow-up of 40%, each study centre was asked to include 35 participants, rendering follow-up data on a total of 84 caregivers.

2.5.2 | Statistical analysis methods

All statistical analyses were performed with STATA version 12.1 (StataCorp). Normally distributed data, such as caregiver burden scale score were presented with means and standard deviations and non-parametric data, such as age, APACHE score, duration of mechanical ventilation, ICU LOS and outcome questionnaire scores with medians and interquartile ranges (IQR). Categorical data, such as sex, admission diagnosis, relation to patient and occurrence of mechanical ventilation were summarized with numbers and percentages. Two-sided significance level was set to 0.05. For comparisons of non-parametric data, the Mann Whitney's U test was used. For comparisons of categorical data, the Chi-square test or Fischer's exact test were used. Linear regression with robust estimates for the standard errors, also adjusting for possible confounding by informal caregivers' sex and age was used to determine mean differences (MD) with 95% confidence intervals (CI) for informal caregiver outcome questionnaire scores. Correlation between non-parametric continuous data was analysed with Spearman's rank correlation coefficient. No imputation was made for missing data.

3 | RESULTS

Among 62 included informal caregivers, the response rate was 89% (55 of 62). The seven caregivers that did not respond were cohabitants to patients who were also dropouts for unknown reasons.

3.1 | Participant data

Of included informal caregivers, 81% were female and a majority (92%) were spouses. Median (IQR) age among caregivers was 63 (47–68). Among the ICU survivors, 18% were female and median age was 64 (46–71). Median APACHE II score was 18 (13–23) and 53% of patients received invasive mechanical ventilation. Median ICU LOS was 3 (1–7) days (Table 1).

3.2 | Patient outcomes

All patients with caregiver follow-up responded ($n=55$), of which 52 had no missing items in the follow-up questionnaires and could be categorised as having or not having an adverse outcome. A total of 17 patients (33%) had adverse psychological and/or physical outcomes according to the predefined criteria (Table 2). The prevalence of substantial symptoms of PTS, depression and anxiety among

TABLE 1 Baseline characteristics for patients and informal caregivers divided by patients with and without adverse outcome and all included patients and caregivers

Baseline characteristic	Patients without adverse outcome n=35	Patients with adverse outcome ^a n=17	All included caregivers/patients n=62
Caregiver data			
Age, median (IQR)	62 (43–66)	64 (52–75)	63 (47–68)
Female sex, n(%)	29 (83)	13 (76)	50 (81)
Relation to patient			
Spouse	32 (91)	17 (100)	57 (92)
Parent	2 (6)	0	2 (3)
Child	1 (3)	0	2 (3)
Sibling	0	0	1 (2)
Patient data			
Age, median (IQR)	62 (46–71)	68 (53–77)	64 (46–71)
Female sex, n(%)	6 (17)	4 (24)	11 (18)
Educational level, n(%)			
Elementary school	5 (15)	8 (47)	14 (23)
Senior high school	13 (38)	3 (18)	21 (34)
University	16 (47)	6 (35)	26 (43)
Occupational status, n(%)			
Employed	15 (43)	5 (29)	27 (43)
Unemployed	2 (6)	0	2 (3)
Retired	17 (49)	10 (59)	30 (48)
On sick leave	1 (3)	2 (12)	3 (5)
Admission diagnosis, n(%)			
Medical	18 (51)	8 (47)	30 (48)
Surgical	16 (46)	7 (41)	28 (45)
Trauma	1 (3)	2 (12)	4 (6)
APACHE II score, median (IQR)	16 (13–24)	22 (17–23)	18 (13–23)
Mechanical ventilation, n(%)	19 (54)	11 (65)	33 (53)
Duration of mechanical ventilation, hours, median (IQR)	185 (72–261)	63(15–157)	81 (32–216)
ICU LOS, days, median (IQR)	3 (1–7)	3 (1–11)	3 (1–7)

Note: IQR Interquartile Range, APACHE Acute Physiology and Chronic Health Evaluation, ICU LOS Intensive Care Unit Length of Stay.

^aDefinition of adverse outcome: HADS Depression subscale score ≥ 11 , HADS Anxiety subscale score ≥ 11 , PTSS-14 part B score >45 and/or BI ≥ 10 score reduction compared to baseline.

patients was 5 (9%), 4 (8%) and 2 (4%) respectively while 13 (24%) patients had an adverse physical outcome.

3.3 | Primary outcome – caregiver burden association with patient outcomes

Caregiver burden was higher for informal caregivers to patients with an adverse outcome compared with caregivers to

patients without an adverse outcome (MD 12.8, 95% CI: 5.7–20) (Figure 1, Table 3). Informal caregivers reporting higher caregiver burden had an increased risk of psychological symptoms and poorer mental HRQL. There were moderate to strong correlations between caregiver burden and informal caregivers' own mental problems, $r_s = 0.68$ (95% CI 0.52–0.84, $P < 0.001$) for depression, $r_s = 0.62$ (95% CI 0.42–0.81, $P < 0.001$) for anxiety and $r_s = 0.72$ (95% CI 0.56–0.89, $P < 0.001$) for PTS. We found a strong negative correlation between caregiver burden

TABLE 2 Follow-up questionnaire scores for patients with and without adverse outcome

Patient outcome questionnaire	Patients with adverse outcome ^a n= 17	Patients without adverse outcome n= 35	p-value
HADS Depression subscale score, median (IQR)	7 (4-10)	1 (1-4)	0.000*
HADS Anxiety subscale score, median (IQR)	3 (3-9)	2 (0-4)	0.016*
PTSS-14 score, median (IQR)	32 (21-46)	20 (18-30)	0.005*
BI score, median (IQR)	80 (45-90)	100 (100-100)	0.000*

Note: HADS, Hospital Anxiety and Depression Scale; IQR, Interquartile Range; PTSS-14, Post-traumatic Stress Syndrome 14-Questions Inventory; BI, Barthel Index.

^aDefinition of adverse outcome: HADS Depression subscale score ≥ 11 , HADS Anxiety subscale score ≥ 11 , PTSS -14 part B score > 45 and/or BI ≥ 10 score reduction compared to baseline.

*Significant p-value, analyzed with the Mann Whitney's U test.

and caregivers' mental HRQL, $r_s = -0.74$, (95% CI -0.9 to -0.6 , $P < 0.001$). For distribution of scores, see Figure 2. A total of 11 (21%) caregivers had clinically significant symptoms of PTS (PTSS-14 part B score > 45), 4 (8%) had substantial symptoms of depression and 8 (15%) of anxiety (HADS subscale score ≥ 11) three months post-ICU. A higher prevalence of PTS was seen for caregivers, when compared to ICU survivors ($P < 0.05$). Compared to baseline, the caregivers overall reported higher MCS score at the 3 months follow-up, median (IQR) 67 (33-83) compared to 73 (42-89), $P = 0.005$.

3.4 | Informal caregivers' sick-leave and days refrained from regular activities

The response rate to the questions regarding sick-leave and days refrained from work or other regular activities was lower than to the validated outcome questionnaires; 45 caregivers responded to

the question concerning days on sick-leave and 42 responded to the question regarding days refrained from work or other regular activities. Among 45 responding informal caregivers, 10 (22%) reported days on sick-leave, mean (SD) 4 (14) days, total range 0-90. Seventeen of 42 respondents (40%) reported days refrained from work or other regular activities due to taking care of their family member, mean (SD) 5 (14) days, total range 0-88. There were no differences in days on sick-leave or refrained from work/other regular activities between informal caregivers to patients with and without an adverse outcome.

The number of informal caregivers responding to the open-ended question regarding additional measures health care could have done to contribute to a better recovery was 33. Ten out of 33 (30%) informal caregivers were satisfied with the help they had received. Sixteen of 33 respondents (48%) wished for more information and support, such as physiotherapy and rehabilitation for the patient and psychological contact and support for informal caregivers during hospitalization.

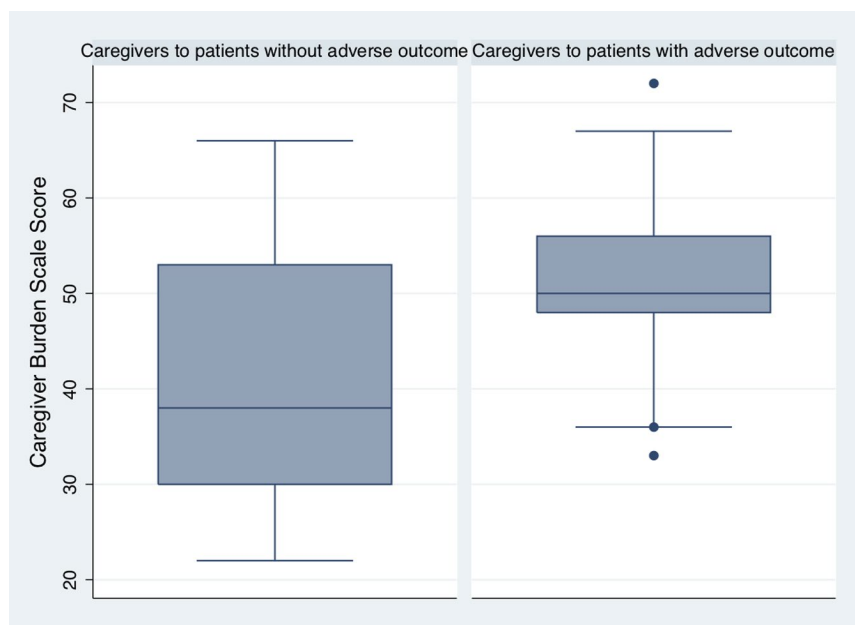


FIGURE 1 Box plot for Caregiver burden scale score for informal caregivers to patients without an adverse outcome and informal caregivers to patients with an adverse outcome

TABLE 3 Outcome scores for informal caregivers to patients with and without adverse outcome with crude and adjusted mean difference

Informal caregiver outcome questionnaire	Informal caregivers to patients with adverse outcome ^a	Informal caregivers to patients without adverse outcome	Crude mean difference	p-value ^b	Adjusted mean difference ^c (95% CI)
CBS Score, mean (\pm SD)	52 (11)	41 (13)	11.2	0.003*	12.81 (5.67 to 19.95)
HADS Depression subscale score, median (IQR)	6 (4–10)	4 (2–7)	1.92	0.085	2.21 (0.05 to 4.36)
HADS Anxiety subscale score, median (IQR)	6 (3–9)	4 (2–9)	1.16	0.383	2.12 (–0.26 to 4.49)
PTSS–14 score, median (IQR)	35 (22–54)	28 (18–38)	6.90	0.239	9.21 (–0.73 to 19.16)
RAND–36 MCS score at follow-up, median (IQR)	53 (37–89)	79 (55–92)	–13.98	0.118	–17.41 (–34.08 to –0.74)

Note: CBS caregiver Burden Scale, SD Standard Deviation, HADS Hospital Anxiety and Depression Scale, IQR Interquartile Range, PTSS–14 Post-Traumatic Stress Syndrome 14-Questions Inventory, MCS Mental Component Score.

^aDefinition of adverse outcome: HADS Depression subscale score ≥ 11 , HADS Anxiety subscale score ≥ 11 , PTSS–14 part B score > 45 and/or BI ≥ 10 score reduction compared to baseline.

^bp-value for the difference between patients with and without adverse outcome from the crude mean difference analysis.

^cAdjusted for informal caregiver age and sex.

*Significant p-value.

3.5 | Missing outcome data

Out of 55 responders, 7 had missing items in the caregiver burden scale. Three caregivers had missing items in the HADS Depression subscale, the HADS Anxiety subscale and the PTSS-14 part B questionnaire. No imputation was made for missing data.

4 | DISCUSSION

In our study, caregiver burden was significantly higher in informal caregivers to patients with an adverse 3-month physical and/or psychological recovery than in those with a favourable patient outcome. A high caregiver burden was associated with more psychological symptoms and worse mental HRQL.

Our findings of a high caregiver burden – linked to more psychological symptoms and poor mental HRQL – in informal caregivers of ICU survivors with an incomplete three-month recovery indicate the potential value to target not only the patient, but also the informal caregiver in the aftercare after critical illness and ICU stay.

Earlier studies have indicated a link between patient and informal caregiver psychological status post-ICU.²⁰ Depressive symptoms in caregivers have been associated with increased caregiver burden.^{7,21} Similar to previous studies, the incidence of symptoms of PTS in informal caregivers was higher than the level of PTS symptoms in patients three months post-ICU.^{9,22} Prevalence of PTS was substantially higher among caregivers than prevalence in a similar aged female population,²³ whereas prevalence of depression and anxiety was in the range of the general population.^{24–26}

The findings in our study indicate a need for management not only of the patient but also of the informal caregivers in follow-up after ICU stay, particularly caregivers to patients at high risk for persisting or new-onset morbidity in the first months post-ICU. Fairly accurate prediction of later physical or psychological problems in ICU survivors is possible.^{11,12} High risk for incomplete recovery in an ICU survivor should alert follow-up teams that informal caregivers may have an increased risk for own problems. We are unaware of any existing ICU follow-up service that screens informal caregivers routinely, or of any specific, systematic support for informal caregivers or family.

Being by the bedside in the ICU when a family member is critically ill may represent the index trauma leading to the development of post-traumatic stress. Informal caregivers with psychological problems and with reduced mental HRQL are likely not in their full capacity to support a recovering ICU survivor. Systematic screening of informal caregivers together with the patient after ICU stay could be valuable with regard to the outcomes of both the caregiver and the patient. Given the findings of our study and prior research, a screening and management plan involving both the patient and informal caregiver deserves study, with regard to improving patient and informal caregiver outcomes.

We anticipated a worsening in mental HRQL from baseline that was not substantiated; instead MCS score was higher at

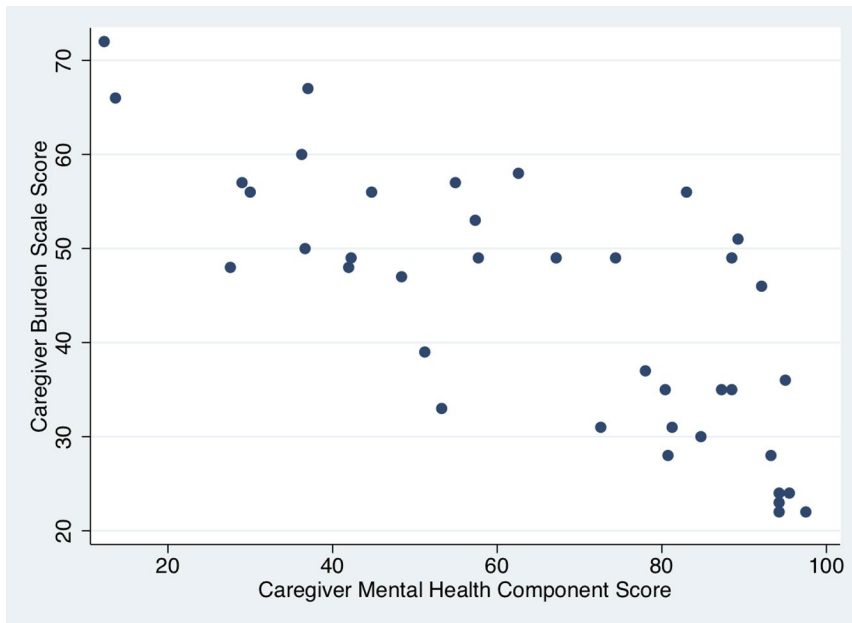


FIGURE 2 Scatter plot of Caregiver burden scale score and informal caregiver RAND-36 Mental health component score

follow-up, indicating better mental HRQL. One explanation may be that “baseline” HRQL, rated when the patient was already admitted to the ICU, did not accurately reflect HRQL before the ICU admission due to responder bias in the current emergency situation. Another possible explanation would be a so called “response shift”, in which the respondent undergoes an internal recalibration of values due to changing circumstances and may rate higher HRQL than expected.²⁷

4.1 | Strengths and limitations

In contrast to several previous studies that restricted caregiver assessment to ICU patients being mechanically ventilated ≥ 48 h or longer,^{28,29} we included informal caregivers to a broad group of ICU patients, admitted for 12 h or longer to mixed medical-surgical ICUs in four different sized hospitals. This is a strength and increases generalizability, given that data do not support the notion that informal caregiver or patient outcomes are linked to the duration of mechanical ventilation or patients' ICU LOS.^{12,30}

Due to the aim and design of this study, informal caregivers to patients that died in the ICU were not included. This could explain the lower prevalence of mental health problems in our study compared to earlier studies. Informal caregivers to bereaved family members have been shown to suffer from psychological problems to a higher extent than informal caregivers to ICU survivors.^{22,31,32}

Sample size was not reached due to limited resources, not permitting an extended inclusion period and more patients than expected fulfilling exclusion criteria, possibly introducing a type II error. Caregivers to patients deceased before the three-month follow-up were excluded since the primary outcome was to evaluate caregiver burden in relation to patient outcome, further reducing the sample size. Despite this, a significantly higher CBS score for caregivers to patients with adverse outcome was found.

Our cohort of caregivers consisted of 80% women, in consistency with previous studies with a majority of female spouse caregivers included,^{7,8,22,33,34} presumably due to more male patients being admitted to the ICU.³⁵ We do not have data on caregivers' comorbidities and previous mental health, neither of caregivers' occupational or educational status or the duration of hospital stay after ICU discharge, which is a limitation. Potential selection bias cannot be completely excluded with the convenience sampling, including informal caregivers who came to the ICU, visiting at research staff work hours and consented to the study.

4.2 | Interpretation

In our study, informal caregivers of patients suffering from PICS mental or physical components reported a greater caregiver burden than those caring for patients with a good physical and psychological outcome. This burden was associated with a higher degree of psychological symptoms and poorer mental HRQL among informal caregivers. Qualitative approaches may potentially elucidate the interplay between the patient and the informal caregiver in the recovery phase, during which the level of patient care and healthcare interventions and support may affect the perceived or real burden for informal caregivers. It appears to be reasonable to screen and follow-up informal caregivers within ICU follow-up programs, particularly those to patients with high risk for a poor recovery.

5 | CONCLUSIONS

Caregiver burden was higher in informal caregivers to ICU survivors with an incomplete physical and/or psychological recovery. A high caregiver burden was associated with worse mental

HRQL. We suggest screening for and managing PICS-F in informal caregivers in ICU follow-up programs, particularly in informal caregivers to ICU survivors with high risk of adverse long-term outcomes.

CONFLICTS OF INTEREST

All authors declare no conflicts of interest.

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