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# Exploring positive aspects of caregiving in family caregivers of adult ICU survivors from ICU to four months post-ICU discharge

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ABSTRACT

*Background:* Despite growing attention to the positive meaning from ICU survivorship, little is known about positive experience among family caregivers of ICU survivors.

*Objectives:* To explore positive aspects of caregiving in family caregivers from patients' ICU admission to 4-month post-ICU discharge.

*Methods:* A secondary analysis of data from 47 family caregivers of ICU patients who self-reported the measure, Positive Aspects of Caregiving (PAC, 11-item, score range 11–55).

*Results:* Family caregivers rated their experience as positive overall across the time points (mean 42.42–44.95). Trends of higher mean PAC scores were observed in caregivers who were older than 50 years of age, parent or sibling of patients, not working, had religious background or preference, and had no financial difficulty. Better social support and psychological responses were associated with PAC.

*Conclusion:* In our sample, family caregivers of ICU survivors rated their caregiving experience as positive during the ICU and post-ICU periods.

## Introduction

With improved therapeutics in the intensive care unit (ICU), the scope of measuring success after critical illness has been shifted from survival in the ICU to achieving long-term functional recovery and quality of life after returning to the community.[1] Along with increased knowledge of long-term physical, psychological and cognitive sequelae common in ICU survivors, clinicians and researchers are more aware of the challenges and needs in family caregivers who are crucial but hidden care partners for this patient population.[2] Family caregivers of the critically ill are under high levels of stress. Illness episodes that lead to ICU admission are unanticipated and life-threatening and family members have no mental preparation for the unfamiliarity of the ICU and the unpredictability of the patient's illness course. This level of uncertainty extends to the period after ICU discharge and family caregivers are at increased risk for adverse physical and mental health outcomes,[3,4] such as depressive symptoms,[5] anxiety,[6] post-traumatic stress,[7] poor self-care,[8] poor sleep,[9] and fatigue.[10] For these reasons, the focus of studies to date have centered on negative outcomes in family caregivers at various stages of critical illness and recovery. Little is known about positive aspects of caregiving in this caregiver population.

According to studies of family caregivers of patients with other chronic conditions (for example, dementia and cancer), caregiving can also involve positive experiences[11,12] such as improved self-esteem, strengthened relationship with care recipients, personal growth, and finding meanings from their roles.[12,13] Positive appraisal of caregiving was suggested to help family caregivers to view their caregiving role as less burdensome and to reduce negative physical and psychological consequences of caregiving.[11] In the field of ICU survivorship, positive coping and growth in both ICU survivors and family caregivers are novel concepts.[14] To promote positive coping in family caregivers, understanding how caregivers view positive aspects of their experience is important. However, few studies have explored positive caregiving experience longitudinally.

Therefore, the aim of this study was to examine (1) positive aspects of caregiving in family caregivers of ICU patients from ICU admission to $<$ 2 weeks, 2 months and 4 months post-ICU discharge, and (2) correlations between positive aspect of caregiving and other psychosocial responses in caregivers including perceived social support, depressive symptoms and anxiety at each time point.

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## Materials and methods

### Study design and data source

We conducted a secondary analysis of data drawn from a longitudinal descriptive study that explored biobehavioral stress responses in family caregivers of adult ICU patients (on mechanical ventilation for ≥ 4 days) from patients' ICU admission to 4 months post-ICU discharge.[15] In the parent study, the major focus was on characterizing psychological responses (e.g., depressive symptoms), altered self-care behaviors (e.g., eating, keeping a doctor appointment), poor sleep quality and fatigue in family caregivers over the course of patients' acute illness and post-ICU recovery.[5,8,10] Positive aspects of caregiving was added to the parent study as an effort to explore caregiver responses beyond a traditional focus of negative responses.

### Sample

In the parent study, a family caregiver was defined as an individual who provided the majority of emotional, financial and physical support to their respective patient. Family caregivers were not required to have legal relation nor cohabitation with the patient. In this report, we use "caregiver" as family caregiver. Caregivers were eligible if they were (1) non-professional, non-paid caregiver, (2) age ≥21 years, (3) having reliable telephone access, and (4) able to read and speak English. Patients eligibility criteria were (1) age ≥21 years, (2) residing at home before ICU admission, (3) on mechanical ventilation for ≥4 consecutive days in a medical ICU, (4) not dependent on mechanical ventilation before this ICU admission.

Detailed information on screening, enrollment and follow-up from the parent study is summarized in Fig. 1. The parent study was an observational study using a convenience sample. Participant recruitment was conducted in a single medical ICU in an abbreviated time span (for 21 months). For this secondary analysis, we used data from 47 cases which both caregivers and patients provided consent.

### Setting and data collection procedure

In the parent study, we conducted participant recruitment and all baseline data collection in the medical ICU of a tertiary academic medical center. In the process of participant recruitment, ICU staff identified potentially eligible family caregivers and asked if they permitted a research team member to approach them. If family caregivers granted permission, a research team member verified eligibility and explained the main purpose, procedures, potential risks and benefits related to study participation. Follow-up data collection took place within 2 weeks after their respective patient was discharged from the ICU and continued at 2 and 4 months post-ICU discharge. Follow-up data collection was conducted in settings where patients lived at each time point.

### Measures

*Positive Aspects of Caregiving* (PAC, 11 items) was used to measure positive responses to providing care.[16] A 5-point Likert-type scale (where 1 = *disagree a lot*, 5 = *agree a lot*) was used to rate the extent of agreement or disagreement to the statement regarding feelings of positive meaning or reward due to caregiving (e.g. "Caregiving experience made me feel important," "Caregiving experience made me feel strong and confident"). Scoring consists of summing scores for each item; higher scores indicating greater rewards from caregiving. Total scores ranged from 11 to 55. Validity was established in caregivers of persons with Alzheimer's disease[16] and primary malignant brain tumor.[17] The Cronbach's alphas in this caregiver sample were .89 –.95.

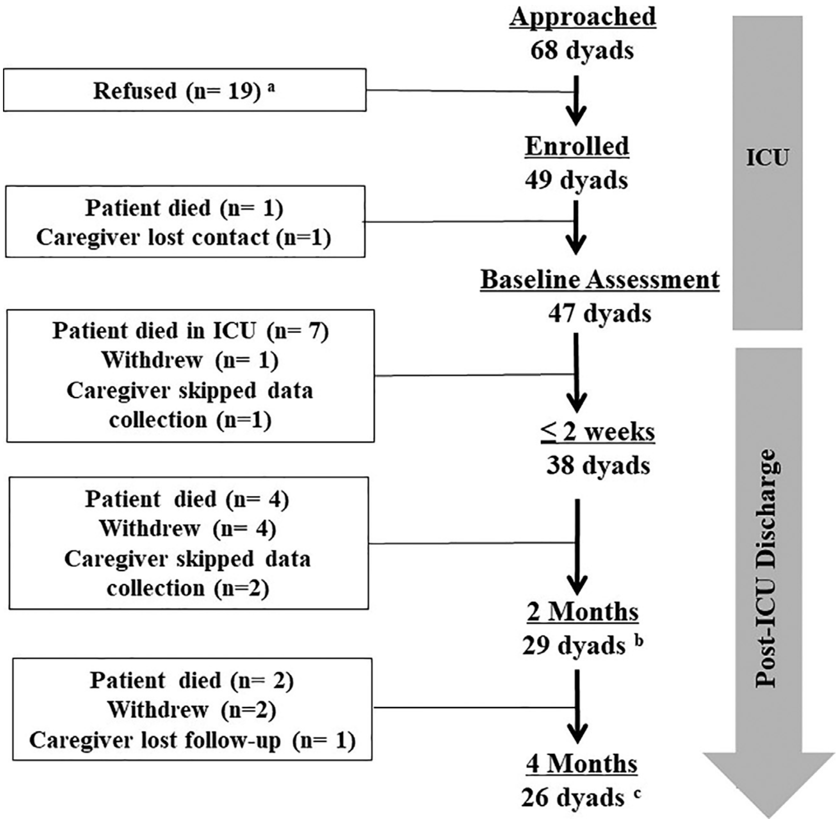

**Fig. 1.** Participants enrollment and follow-up. [a]Reasons for refusal include:" too busy (n = 10), feel stressed (n = 4), other family members disagree (n = 2), "not interested (n = 2) and "not feel comfortable (n = 1). [b]A total of 29 participated at 2 months because caregiver who skipped data collection at 2 weeks (n = 1) responded at 2 months. [c]A total of 26 participated at 4 months because caregiver who skipped data collection at 2 months (n = 2) responded at 4 months.

*Modified Interpersonal Evaluation List* (Modified ISEL, 10 items) was used to measure perceived social support.[18] A 4-point scale was used for each item (where 1 = *definitely false*, 4 = *definitely true*). Caregivers were asked to rate availability types of social support, such as perceived availability of person to discuss problems (e.g., “There is someone I can turn to for advice about handling family problems”). Total scores ranged from 10 to 40, with higher scores indicating more social support. Validity was established using other measures of social support.[18,19] Social support has linked with burden[20] and depressive symptoms[21] in caregivers of persons with traumatic brain injury. The Cronbach’s alphas in this caregiver sample were 0.93 − 0.97.

*Shortened Version of Center for Epidemiologic Studies-Depression 10-items* (CESD-10) was administered to measure depressive symptoms.[22] A 4-point Likert-type scale was used for each item. Total score ranged from 0 to 30. Higher scores indicate worse depressive symptoms. The CESD has been used extensively with family caregivers of dementia patients[23] and cancer patients.[24,25] The Cronbach’s alphas in this caregiver sample were 0.86–0.93.

*Shortened profile of mood states-anxiety scale* (POMS-A) was administered to measure symptoms of anxiety. The original POMS is an instrument to assess transient mood states.[26,27] In the present study, we used the 3-item tension-anxiety subscale. A 5-point scale (where 1 = *never*, 5= *always*) was used for each item. The total score ranged from 3 to 15. Higher scores indicate worse anxiety symptoms. Validity has been established with other anxiety measures.[28] The Cronbach’s alphas in this caregiver sample were 0.85–0.93.

### *Ethics and formal requirements*

The study protocol was reviewed and approved by the institutional review board. All participants provided written informed consent.

### *Data analyses*

A member of the research team manually entered data into the IBM SPSS v.23.0 for Windows and the principal investigator (JC) verified all entry. Descriptive statistics, such as mean, *SD* and frequency, were reported for all variables. Considering the small sample size, we used non-parametric statistics to provide a conservative interpretation. Spearman’s rank correlation was used to examine the associations between the total score of PAC and the measures of perceived social support (Modified ISEL), depressive symptoms (CESD-10) and anxiety (POMS-A). For caregivers who participated in data collection for all four time points, Friedman test was used to explore longitudinal change in the PAC scores. We also explored trends of differences in mean PAC scores by the following family caregiver characteristics: caregiver age (age <50 years vs. age ≥50 years), sex (men vs. women), relationship to patients (spouse or significant other vs. adult child vs. parent or sibling), employment status (working full or part time vs. not working), religion (having religious background or preference vs. not having religious background or preference), and perceived economic hardship (having no difficulty in paying for needs vs. having difficulty in paying for needs). Because the purpose of this secondary analysis was to describe experiences of family caregivers of the critically ill from a new perspective, we explored both statistical significance ($\alpha = 0.05$, two-tailed) and trends in differences.

## Results

### *Sample characteristics*

In Table 1, we summarized participant characteristics and scores of measures at each time point. Caregivers were mostly Caucasian women with a mean age of 52 (*SD* = 12.1) years. The vast majority of them were a spouse, significant other or adult child of the patient. Patients were mostly Caucasian men with a mean age of 56 (*SD* = 16.7) years. As reported previously, attrition occurred during the study period mainly due to patient death.[10] At 2 weeks ($n = 1$) and 2 months ($n = 2$), there were caregivers who skipped a data collection point but remained in the study and participated in the subsequent data collection points (Fig. 1). Considering these cases, a total of 23 caregivers participated in all four data collections from ICU admission to 4 months post-ICU discharge. There was no significant difference in characteristics in caregivers who remained in the study and those who were lost to attrition.[10]

### *Positive aspects of caregiving and its correlation with perceived social support, depressive symptoms and anxiety*

Regarding the scores of the PAC, mean scores ranged from 42.42 to 44.95 (see Table 1). In our sample, 23 caregivers responded to the PAC measures for all four time points. When we explored longitudinal changes in PAC scores in this subsample, there was no significant change from ICU admission to 4 months post-ICU discharge [Friedman test $X^2(3) = 1.54$, $p = 0.67$]. Regarding correlations between the PAC score and other caregiver variables, directions of correlations were consistent across the time points; higher PAC scores were associated with better perceived social support, less depressive symptoms and less anxiety (see Table 2). At 2 weeks and 2 months post-ICU discharge, higher PAC score was significantly associated with better mastery, better perceived social support, less depressive symptoms and anxiety in caregivers (all $p < 0.05$).

### *Positive aspects of caregiving by each item scores*

In Table 3, we described mean and *SD* of each item in the PAC by a timeline. Across the timeline, there were items having mean scores of greater than 4 (“agree”), such as “feel needed,” “appreciate life more,” “develop a more positive attitude toward life.” There were also items that mean scores showed decreasing trends over time, such as “given more meaning to my life,” and “strengthened relationship with others.” Regarding the item “enable me to learn new skills,” mean scores tended to be higher during post-ICU period compared with the baseline. We also explored longitudinal trends of item scores in 23 caregivers who responded to all 4 time points using Friedman test and changes were not statistically significant.

### *Comparison of trends in pac scores by caregiver characteristics*

We compared the mean PAC scores at each time point grouped by caregiver characteristics. We observed trends of higher mean PAC scores in family caregivers with the following characteristics: older than 50 years of age, parent or sibling of the patient, having religious background or preference, reporting no difficulty in paying for needs and not working. However, none of these trends was statistically significant.

## Discussion

In this longitudinal study, we explored positive aspects of caregiving in caregivers of ICU survivors and its association with caregivers’ perceived social support, depressive symptoms and anxiety from patients’ ICU admission to 4 months post-ICU discharge. In our sample, the mean scores of the PAC across the time points indicate a majority of caregivers positively rated their caregiving experience. The PAC scores initially measured during patient’s ICU admission remained stable for 4 months follow-up period. At ≤2 weeks and 2 months post-ICU discharge, higher score of PAC was significantly associated with greater perceived social support and lower symptoms of depression and anxiety. As an effort to learn more on this rarely studied topic area, we also described trends in each item of the PAC and compared the score trends by selected caregiver characteristics. We observed trends of higher mean PAC scores in family

**Table 1**
Demographic and clinical characteristics of caregiver-patient dyads from ICU admission to 4 months post-ICU discharge

| Characteristics | ICU admission (Enrollment) (n = 47) | ≤2 weeks Post-ICU discharge (n = 38)[a] | 2 months Post-ICU discharge (n = 29)[b] | 4 months Post-ICU discharge (n = 26)[c] |
|---|---|---|---|---|
| | n (%) or M ±SD | n (%) or M ±SD | n (%) or M ±SD | n (%) or M ±SD |
| **Caregiver** | | | | |
| Age (years) | 51.91 ± 12.08 | 50.92 ± 12.43 | 50.00 ± 12.66 | 50.88 ± 11.21 |
| Gender (Men) | 12 (25.5) | 8 (21.1) | 7 (24.1) | 5 (19.2) |
| Ethnicity, Caucasian | 44 (93.6) | 35 (92.1) | 28 (96.6) | 26 (100.0) |
| Relationship to patient | | | | |
| Spouse or significant other | 27 (57.4) | 21 (55.3) | 17 (58.6) | 15 (57.7) |
| Adult child | 12 (25.5) | 10 (26.3) | 6 (20.7) | 5 (19.2) |
| Parent or sibling | 8 (17.0) | 7 (18.4) | 6 (20.7) | 6 (23.1) |
| Employment | | | | |
| Working full time or part time | 26 (55.3) | 21 (55.3) | 17 (58.6) | 14 (53.8) |
| Not working | 21 (44.7) | 17 (44.7) | 12 (41.4) | 12 (46.2) |
| Having religious background or preference (Yes) | 38 (80.9) | 31 (81.6) | 23 (79.3) | 21 (80.8) |
| Difficulty paying for needs | | | | |
| Not at all difficult | 21(44.7) | 16 (42.1) | 12 (41.4) | 13 (50.0) |
| Extremely or somewhat difficult | 26 (55.3) | 22 (57.9) | 17 (58.6) | 13 (50.0) |
| Positive aspect of caregiving (PAC) | 44.10 ± 7.74 | 44.95 ± 8.39 | 43.69 ± 9.80 | 42.42 ± 8.18 |
| Social support (Modified ISEL) | 32.85 ± 6.79 | 32.53 ± 7.44 | 32.72 ± 8.08 | 31.73 ± 6.95 |
| Depression (CESD-10) | 16.65 ± 7.16 | 10.63 ± 6.05 | 10.31 ± 6.07 | 10.00 ± 7.81 |
| Anxiety (POMS-Anxiety) | 10.06 ± 2.91 | 7.92 ± 2.48 | 7.52 ± 2.73 | 7.62 ± 3.06 |
| **Patient** | | | | |
| Age (years) | 55.45 ± 16.71 | 54.82 ± 17.15 | 51.52 ± 16.34 | 51.81 ± 15.79 |
| Gender (Men) | 31 (66.0) | 25 (65.8) | 21 (67.7) | 19 (70.4) |
| Ethnicity, Caucasian | 44 (93.6) | 35 (92.1) | 28 (96.6) | 27 (100.0) |
| Primary diagnosis | | | | |
| Respiratory | 26 (55.3) | 23 (60.5) | 17 (58.6) | 17 (65.4) |
| Sepsis/ multisystem failure | 9 (19.2) | 6 (15.8) | 3 (10.3) | 1 (3.8) |
| Gastrointestinal/ Hepatic | 8 (17.0) | 6 (15.8) | 5 (17.2) | 4 (15.4) |
| Others | 4 (8.5) | 3 (7.9) | 4 (13.8) | 4 (15.4) |
| Charlson comorbidity score | 4.1 ± 3.3 | 3.82 ± 3.48 | 3.34 ± 3.53 | 2.92 ± 2.84 |
| APACHE II score | 21.6 ± 8.0 | 21.84 ± 7.80 | 21.86 ± 8.57 | 20.00 ± 7.42 |
| ICU length of stay, days | 22.9 ± 13.7 | 25.08 ± 13.36 | 24.46 ± 12.89 | 22.64 ± 10.25 |
| Days on mechanical ventilation | 20.1 ± 13.1 | 21.89 ± 13.21 | 21.52 ± 12.27 | 19.27 ± 9.73 |

*Note*. SD = standard deviation; Modified ISEL= Interpersonal Evaluation List; CESD-10= Center for Epidemiologic Studies-Depression 10-item version; POMS-Anxiety= Profile of Mood States-Anxiety 3 items; ICU = intensive care unit; APACHE = acute physiology and chronic health evaluation.

[a] n=38 due to attrition: Patient died in ICU (n=7), withdrew (n=1), caregiver skipped data collection (n=1).

[b] n=29 due to (1) attrition: Patient died (n=4), withdrew (n=4), caregiver skipped data collection (n=2), and (2) addition of a caregiver who skipped data collection at 2 weeks (n=1).

[c] n=26 due to (1) attrition: Patient died (n=2), withdrew (n=2), caregiver lost follow-up (n=1), and (2) addition of caregivers who skipped data collection at 2 months (n=2)

caregivers who were older than 50 years of age, parents or siblings of patients, and having religious backgrounds or preferences, reporting no difficulty in paying for needs and not working. This present study is one of the first studies that longitudinally explored the topic of positive aspects of caregiving in family caregivers of ICU survivors. Trends observed in this sample are worthy of further investigation in a larger sample.

Caregivers are known as integral care partners of the critically ill, but research on psychological and physical outcomes of family caregivers of ICU survivors is in its infancy.[29,30] Our findings increase understanding by describing the positive caregiving experience during ICU hospitalization and recovery after ICU discharge. While little is known about how family caregivers of ICU survivors find positive meaning and reward from their experience, prior studies were conducted mostly in caregivers of individuals with cancer or dementia.[31] Giving care for persons with dementia mainly involves irreversible deterioration in their care recipients while variability exists in timing of deterioration.[32] In cancer, depending on types and stages of the cancer, some caregivers may be in a care situation which limited time with their loved one is more obvious. In our sample, like typical post-ICU trajectories, caregivers faced uncertain and fluctuating care situations, such as delayed recovery of physical and cognitive function, hospital readmission, prolonged institutional care (e.g., long-term acute care hospital, skilled nursing facility). Despite these challenges, a vast majority of our participants rated their caregiving experience as positive. According to prior qualitative report about caregivers' experience after patients' home discharge, patients' physical, emotional and cognitive recovery was much slower than expected in most cases,[33] but our results suggest that caregivers maintained a positive appraisal of their experience.

Studies with cancer caregivers have reported factors that support positive caregiving experience, including daily enrichment strategies (e.g., taking time out for self), hope, social support, religious coping, etc.[11] Because of the small sample size, it was not feasible to examine causal relationships among positive aspects of caregiving, social support and psychological outcomes, but analysis revealed consistent direction of correlations among those variables. Further research is warranted to identify factors influencing positive caregiving experience, which may be targets of future intervention.

Because positive aspects of caregiving is an under-explored topic, there are still many unanswered questions. It is unknown whether positive caregiving experience is a stable trait or time- or situation-varying response. In the present study, the results of subsample analysis showed no statistically significant change for 4 months, but our data are too small to give conclusive answer to this question. The relationship between caregiver characteristics and positive caregiving experience may reveal caregiver characteristics that may be associated with more positive caregiving experience. As an effort to shed light on these questions, we explored item scores in the PAC as well as trends of the differences in mean PAC scores by caregiver characteristics. Results of these trends need cautious interpretation but could provide important guidance for future studies with a larger sample. For example, these caregivers tended to rate items about "meaning to life," and "relationship with others" lower over time.

**Table 2**
Item description and change in the PAC over time

| PAC Item | ICU admission (Enrollment) (n = 47) | ≤ 2 weeks Post-ICU discharge (n = 38)[a] | 2 months Post-ICU discharge (n = 29)[b] | 4 months Post-ICU discharge (n = 26)[c] | p[*] |
|---|---|---|---|---|---|
| | M ±SD | M ±SD | M ±SD | M ±SD | |
| 1. Caregiving experience made me feel more useful. | 4.00 ± 1.10 | 3.97 ± 0.97 | 4.10 ± 1.14 | 3.92 ± 1.13 | 0.53 |
| 2. Caregiving experience made me feel good about self. | 4.06 ± 1.01 | 4.18 ± 1.06 | 4.03 ± 1.05 | 3.96 ± 1.18 | 0.47 |
| 3. Caregiving experience made me feel needed. | 4.23 ± 0.84 | 4.26 ± 1.00 | 4.14 ± 0.92 | 4.12 ± 1.18 | 0.99 |
| 4. Caregiving experience made me feel appreciated. | 4.06 ± 0.92 | 4.26 ± 0.95 | 4.14 ± 0.95 | 3.96 ± 1.00 | 0.58 |
| 5. Caregiving experience made me feel important. | 3.43 ± 1.33 | 3.58 ± 0.98 | 3.48 ± 1.18 | 3.27 ± 1.22 | 0.32 |
| 6. Caregiving experience made me feel strong and confident. | 3.66 ± 1.09 | 3.79 ± 1.12 | 3.69 ± 1.07 | 3.50 ± 1.10 | 0.69 |
| 7. Caregiving experience has given more meaning to my life. | 3.94 ± 0.96 | 3.87 ± 1.17 | 3.66 ± 1.32 | 3.58 ± 1.17 | 0.34 |
| 8. Caregiving experience has enable me to learn new skills. | 3.89 ± 1.13 | 4.08 ± 1.22 | 3.97 ± 1.18 | 4.00 ± 0.98 | 0.65 |
| 9. Caregiving experience made me appreciate life more. | 4.45 ± 0.97 | 4.58 ± 0.79 | 4.45 ± 1.02 | 4.42 ± 0.86 | 0.63 |
| 10. Caregiving experience has enabled me to develop a more positive attitude toward life. | 4.23 ± 0.98 | 4.32 ± 0.87 | 4.14 ± 1.09 | 4.00 ± 0.89 | 0.48 |
| 11. Caregiving experience strengthened my relationship with others. | 4.15 ± 1.02 | 4.05 ± 0.96 | 3.90 ± 1.21 | 3.69 ± 1.12 | 0.39 |
| Total score | 44.10 ± 7.74 | 44.95 ± 8.39 | 43.69 ± 9.80 | 42.42 ± 8.18 | 0.67 |

*Note*. PAC, Positive Aspects of Caregiving.

[*] *Friedman* test *p* value for caregivers who responded to PAC measure at all four data collection points (n = 23).

[a] n = 38 due to attrition: Patient died in ICU (n = 7), withdrew (n = 1), caregiver skipped data collection (n = 1).

[b] n = 29 due to (1) attrition: Patient died (n = 4), withdrew (n = 4), caregiver skipped data collection (n = 2), and (2) addition of a caregiver who skipped data collection at 2 weeks (n = 1).

[c] n = 26 due to (1) attrition: Patient died (n = 2), withdrew (n = 2), caregiver lost follow-up (n = 1), and (2) addition of caregivers who skipped data collection at 2 months (n = 2)

Helping caregivers to find meaning to their life or find ways to sustain supportive relationships with others may be a target of future intervention. On the other hand, items on "feel needed," "made me appreciate life more," and "develop a more positive attitude toward life" had mean scores of greater than 4 out of 5 for all time points. This results suggest our caregivers consistently rated their caregiving experience helped them to maintain a positive outlook on life overall. It will be worth examining factors influencing this positive outlook on life in this caregiver population.

Questions regarding the possibility of future interventions include if an intervention can help family caregivers to gain a more positive outlook toward their experience. In addition, there is no evidence to suggest that staying positive about the caregiving experience can lead to better outcomes in caregivers physical and mental health or patients' recovery.[14,34,35] It may be valuable to examine the influence of resilience or hope on the positive caregiving experience or vice versa. During the acute phase of critical illness in the ICU, in addition to helping family members being aware of ICU environment and engaging in care activities,[36] existing resources such as the hospital chaplain, may be useful to help family caregivers focus on redirecting their focus to more positive aspects of their experience. While findings of the present study suggest an association between perceived social support and positive caregiving experience, some caregivers may not have tangible social support nearby. Advancement in information technology may provide a practical and affordable means to facilitate social support at a distance, for example, joining an online peer support group or teleconferencing with remote family members[37] may improve positive caregiving experience.

The present study contains several limitations. First, this is a secondary analysis of a study with a small sample recruited in a single medical ICU setting. Caregivers who refused to participate may have

**Table 3**
Correlations between the PAC score and scores of the measures of perceived social support, depressive symptoms and anxiety

| Variables | ICU admission (Enrollment) (n = 47) | ≤2 weeks Post-ICU discharge (n = 38) [a] | 2 months Post-ICU discharge (n = 29) [b] | 4 months Post-ICU discharge (n = 26)[c] |
|---|---|---|---|---|
| | *r* (*p*) | *r* (*p*) | *r* (*p*) | *r* (*p*) |
| Perceived Social Support (Modified ISEL) | 0.20 (0.19) | 0.40 (0.02) | 0.51 (0.01) | 0.16 (0.48) |
| Depressive symptoms (CESD-10) | −0.20 (0.18) | −0.42 (0.01) | −0.41 (0.03) | −0.17 (0.42) |
| Anxiety (POMS-Anxiety) | −0.10 (0.52) | −0.39 (0.02) | −0.52 (0.004) | −0.27 (0.18) |

PAC=Positive Aspects of Caregiving; ISEL= Interpersonal Evaluation List; CESD= Center for Epidemiologic Studies Depression; POMS= Profile of Mood States.
*r* = Spearman's *rho.*

[a] n = 38 due to attrition: Patient died in ICU (n = 7), withdrew (n = 1), caregiver skipped data collection (n = 1).

[b] n = 29 due to (1) attrition: Patient died (n = 4), withdrew (n = 4), caregiver skipped data collection (n = 2), and (2) addition of a caregiver who skipped data collection at 2 weeks (n = 1).

[c] n = 26 due to (1) attrition: Patient died (n = 2), withdrew (n = 2), caregiver lost follow-up (n = 1), and (2) addition of caregivers who skipped data collection at 2 months (n = 2)

different responses. Because the focus was on the experience of caregivers of survivors, we discontinued following caregivers if the patient died during the study period. For these reasons, the limited sample size prohibited identification of causal relationships between the scores of PAC and other associated variables (e.g., social support). Instead, we kept our focus in reporting a descriptive illustration of caregiver responses within the follow-up time frame, from ICU to 4 months post-ICU discharge. Without involving a longer follow-up period, it is unclear whether the PAC is a stable condition or a changeable condition over the long-term, although PAC scores tended to be stable over time in this small sample. The associations of patient clinical characteristics (e.g., Charlson Comorbidity Index score, ICU length of stay, days on mechanical ventilation) and caregivers' PAC scores were explored but yielded no meaningful correlations. Again, the small sample size limited the ability to identify potential influence of the patient's illness profile on PAC scores. Second, a majority of the study participants were Caucasian. According to findings from previous studies, African American caregivers were more positive about their caregiving experience than caregivers of other races.[38-40] Considering the potential influence of socio-cultural expectations of the caregiving role, our results need cautious interpretation.

## Conclusion

Little is known about positive caregiving experience in caregivers of ICU survivors. In the present study, family caregivers of ICU survivors rated their caregiving experience as positive during both the ICU and post-ICU period. Our results suggest caregivers' positive experience may be associated with greater social support and better psychological responses at within 2 weeks and 2 months post-ICU discharge. Findings from our exploratory analyses also suggest importance of further identifying how caregivers positively appraise their experience and how caregivers' positive appraisal can differ by caregiver characteristics. Mixed method approaches will be a valuable next step to understand what makes the caregiving experience positive and whether having positive experience takes a protective role to caregivers' physical and mental health.

## Declaration of Competing Interest

No conflict of interest has been declared by the authors.

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## Ethical approval

The study protocol was reviewed and approved by the University of Pittsburgh Institutional Review Board (PRO08060034). All participants provided informed consents.

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