



# POSITIVE APPRAISAL OF CAREGIVING FOR INTENSIVE CARE UNIT SURVIVORS: A QUALITATIVE SECONDARY ANALYSIS

By Judith A. Tate, PhD, RN, and JiYeon Choi, PhD, RN

**Background** More than half of intensive care unit survivors require assistance from family caregivers after discharge. Caregiving is associated with negative consequences including poor health-related quality of life, psychosocial distress, and burden. Little is known about how family caregivers find satisfaction and meaning in their experience.

**Objectives** To explore positive descriptions of the experiences of family caregivers of critically ill patients and to describe factors that family caregivers view as important to a positive caregiving experience from hospitalization to 4 months after discharge.

**Methods** Qualitative secondary analysis was performed on data from semistructured interviews conducted as part of a longitudinal study that examined physical and psychological responses to stress in a convenience sample of family caregivers of adult intensive care unit patients who underwent prolonged mechanical ventilation ( $\geq 4$  days). Interviews were conducted at 4 time points: during the hospitalization and within 2 weeks, 2 months, and 4 months after discharge.

**Results** Participants ( $n=41$ ) reported factors that helped them positively appraise their caregiving experience in 113 interviews conducted face to face or via telephone. During patients' hospitalization, caregivers described changes in their role, with their primary responsibility being to advocate for the patient. They described how this experience fulfilled their identity and strengthened their relationship with the patient. Most family caregivers mentioned the importance of social support and prayer.

**Conclusions** Family caregivers of intensive care unit patients can identify positive aspects of caregiving during the experience. Interventions to reframe the caregiving experience in a positive light are warranted. (*American Journal of Critical Care*. 2020;29:340-349)

**I**ncreasing numbers of individuals survive the critical phase of illness owing to advanced therapeutics and management in the intensive care unit (ICU).<sup>1</sup> Physical, emotional, and cognitive sequelae challenge ICU survivors because these problems adversely affect their daily functioning and quality of life for months and years after ICU discharge.<sup>2-8</sup> With growing awareness of this constellation of conditions, called post-intensive care syndrome, researchers and clinicians have given increasing attention to the family caregiver, a valuable but underrecognized care partner.<sup>9</sup>

Having a critically ill loved one in an ICU is a highly stressful experience for families.<sup>10</sup> With the serious and unpredictable nature of illnesses that lead to an ICU admission, many family caregivers deal with physical and emotional challenges for which they are unprepared.<sup>11,12</sup> In addition to their responsibilities as advocates and decision makers, family caregivers witness the responses of the patient to the ICU environment. Thus, family caregivers are also at risk for negative sequelae, known as post-intensive care syndrome-family, as a result of their own experiences during and after the patient's ICU stay.<sup>4,9,13-15</sup>

Family caregiving is a critical component of ICU survivorship that involves direct physical and psychological care of the patient, shouldering additional home and family responsibilities, and serving as an advocate as the patient recovers. Most research to date on family caregivers of ICU survivors has focused on their distress and burden.<sup>15-19</sup> This focus may provide a limited view of caregiving and miss acknowledging the possibilities of adaptation. Few studies have focused exclusively on the positive aspects of the caregiving experience among family caregivers of ICU survivors.

We reexamined longitudinal qualitative interview data from family caregivers of critically ill patients to achieve the following aims: (1) to explore positive descriptions of the family caregiving experiences and (2) to describe factors that family caregivers view as important to a positive caregiving experience from ICU hospitalization to 4 months after ICU discharge.

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#### Methods

This study used a secondary analysis of semi-structured narrative interview data from a parent study that examined physical and psychological stress responses in family caregivers of adult ICU patients who underwent prolonged mechanical ventilation ( $\geq 4$  days) from patients' ICU hospitalization to 4 months after ICU discharge.<sup>6</sup> Additional details of the parent study have been reported elsewhere.<sup>6-8,20,21</sup> The protocol of the parent study was reviewed and approved by the institutional review board at the University of Pittsburgh. In the parent study, all family caregiver participants provided written informed consent.

#### Sample

In the parent study, we defined *family caregiver* as an individual who provided the majority of support, including emotional, physical, and/or financial support, to a given patient. Having a legal relationship or cohabitation with the patient was not required. In this report, we use *caregiver* to refer to a family caregiver. Eligibility criteria for caregivers were (1) being a nonprofessional, unpaid caregiver, (2) aged 21 years or older, (3) having reliable telephone access, and (4) being able to read and speak English. Patient eligibility criteria were (1) aged 21 years or older, (2) residing at home before ICU admission, (3) having received mechanical ventilation for 4 or more consecutive days in a medical ICU, and (4) not being dependent on mechanical ventilation before this ICU hospitalization. The rationale for choosing a duration of mechanical ventilation of 4 or more consecutive days has been described elsewhere.<sup>22</sup> In the parent study, qualitative interviews were an option for caregivers. In this secondary analysis, we used data from 41 caregivers who participated in qualitative interviews.

**“It’s a relief to know that my family is taking care of things at home so I can stay here with him.”**

## Interviews and Data Collection

In the parent study, 1 trained research team member (J.C.) interviewed caregivers at 4 time points: during the ICU hospitalization (baseline) and within 2 weeks, 2 months, and 4 months after ICU discharge. The details of data collection location at each time point have been reported elsewhere.<sup>23</sup> We used semi-structured interviews to determine the general caregiving experience and changes in the caregivers' lives and relationships with others at each time point.<sup>6</sup> At the beginning of each interview, caregivers were asked to describe their typical day, and then they were asked questions about the caregiving experience (eg, "What makes your caregiving difficult or easy?"). All interviews used the same questions, and the interviewer used probes to elicit additional details about the caregivers' experience. Interviews were audiotaped, transcribed verbatim, and imported into the research software program ATLAS.Ti (ATLAS.Ti Scientific Software Development) for data management.

## Data Analysis

The primary author (J.C.) and a team member (J.A.T.) with extensive experience in qualitative methods conducted the analysis. We used manifest content analysis to determine predominant concepts or texts to identify recurring themes.<sup>24</sup> To develop the codebook, we analyzed interviews from all time points and with caregivers having varied relationships with patient participants. We developed codes by returning to the data repeatedly<sup>25</sup> and selected codes that indicated positive experiences of caregivers. Together, we reviewed 25% of all interviews from each case to develop definitions, boundaries, and examples of codes; review exemplary quotations; and finalize the codebook. Each of us

**"Our friends and family supported us with prayer."**

independently coded the remaining interview data, and we met regularly to review and compare the independent coding for consistency. Additionally, we examined and discussed negative cases, that is, interviews that had no examples of positive appraisal of caregiving. We then collapsed codes into themes. We returned to the data to identify relationships and dimensions of positive aspects of caregiving, important influences and responses from the caregiver perspective, and additional contextual conditions and consequences.<sup>26</sup> We reexamined these themes and dimensions over time and developed a process model to illustrate how family caregivers described what led them to appraise caregiving in a positive light. We also analyzed how these themes

changed over the 4 interview time points. Thematic frequencies were recorded in ATLAS.ti and transferred to a spreadsheet.

We maintained methodological rigor and trustworthiness in the following ways. First, we maintained an audit trail of methodological notes and analytical decisions. Prolonged engagement with the participants over the 4-month follow-up period by the principal investigator enhanced our ability to understand the phenomenon of caregiving over time as patient conditions and care context changed. We reviewed and critiqued analytical decisions during weekly meetings, which augmented credibility. Although the original sample was a convenience sample drawn from participants in a primarily quantitative study, the final interview sample provided thick, rich descriptions of experiences and perspectives of caregiving, enhancing transferability. Finally, we recognized that our extensive clinical experience in the ICU and previous research with patients receiving mechanical ventilation and their families might influence the analysis of the data. We attempted to minimize this influence by using reflexivity during analytical sessions to prioritize the voice of the caregivers rather than any preconceived notions of researchers.

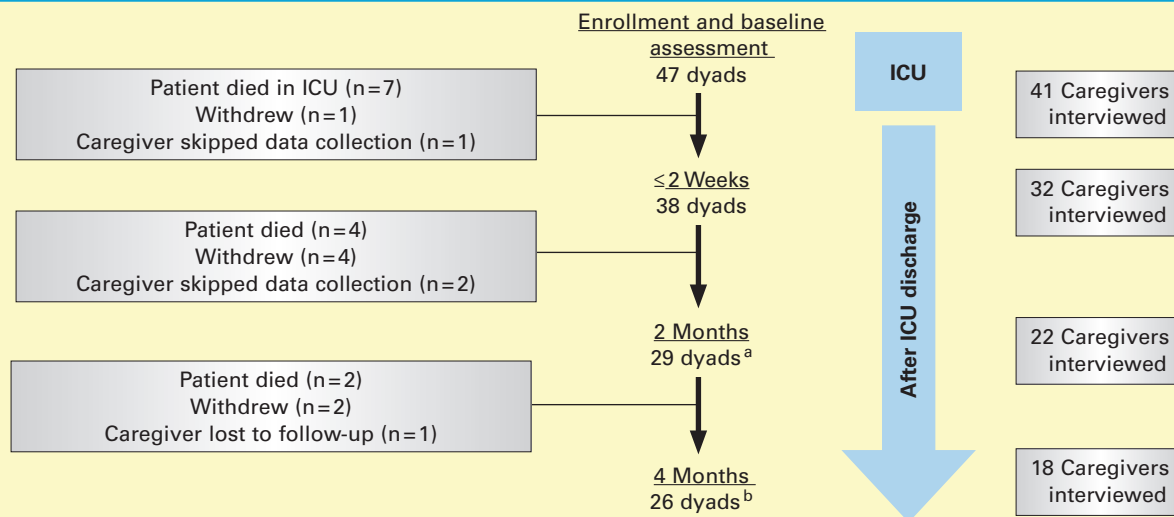
## Results

### Sample Characteristics

Information on recruitment and retention of caregiver and patient dyads in the parent study and the proportion of caregivers who participated in the qualitative interviews at each time point is shown in Figure 1. We reviewed 113 transcripts from 41 caregivers. Sample characteristics are summarized in Table 1. Caregivers were mostly female ( $n = 31$ , 76%), middle-aged (mean [SD] age, 51.88 [12.22] years), and the spouse or significant other of the patient ( $n = 23$ , 56%). Patients were mostly male ( $n = 28$ , 68%) and middle-aged (mean [SD] age, 54.76 [17.18] years). Patients received mechanical ventilation for a mean (SD) of 21.15 (13.55) days during their ICU hospitalization. Respiratory failure was the most common ICU admission diagnosis ( $n = 22$ , 54%).

### Main Themes

We identified a process model of positive appraisal of caregiving based on longitudinal data from our sample. Concepts included role and relationship, caregiver identity, patient communication, social support for the caregiver, and prayer and faith (Figure 2). Exemplar quotations from caregivers for each of these concepts are shown in Table 2.



**Figure 1** Enrollment and follow-up of participants in the study.

Abbreviation: ICU, intensive care unit.

<sup>a</sup>A total of 29 participated at 2 months because caregiver who skipped data collection at ≤2 weeks (n=1) responded at 2 months.

<sup>b</sup>A total of 26 participated at 4 months because caregiver who skipped data collection at 2 months (n=2) responded at 4 months.

**Role and Relationship.** Many caregivers described the critical illness as an event that created an abrupt shift in their roles and relationship with the patient. The dyadic role (eg, spouse) was acutely disrupted with the caregiver's uncertainty whether the patient would ever resume their preillness role. Caregivers described this experience as most profound in interviews conducted in the ICU. In the interviews after ICU discharge, caregivers viewed incremental return of the patient's role (eg, returning to work, resuming social interactions) as evidence of improvement in the patient's overall physical and cognitive condition. These signs of improvement added to caregivers' perceptions of accomplishment:

If I asked him to do something—a lot of times he knows I come home from work, he'll go down and throw a load of clothes into the wash or he'll put towels into the washer and dry them and bring them up for me or help me with things. So it's a closer relationship than what it was.  
(Mother, 4 months)

Caregivers took on roles and responsibilities previously shared with or the sole responsibility of the patient. Many caregivers described the difficulty in balancing these new responsibilities and their own work responsibilities with the need to be present at the patient's bedside.

Family caregivers viewed their role in the acute phase as being the patient's voice or advocate. Their continued presence in the ICU waiting room was an extension of this responsibility. On advice she would give to other families, a daughter said during the ICU hospitalization:

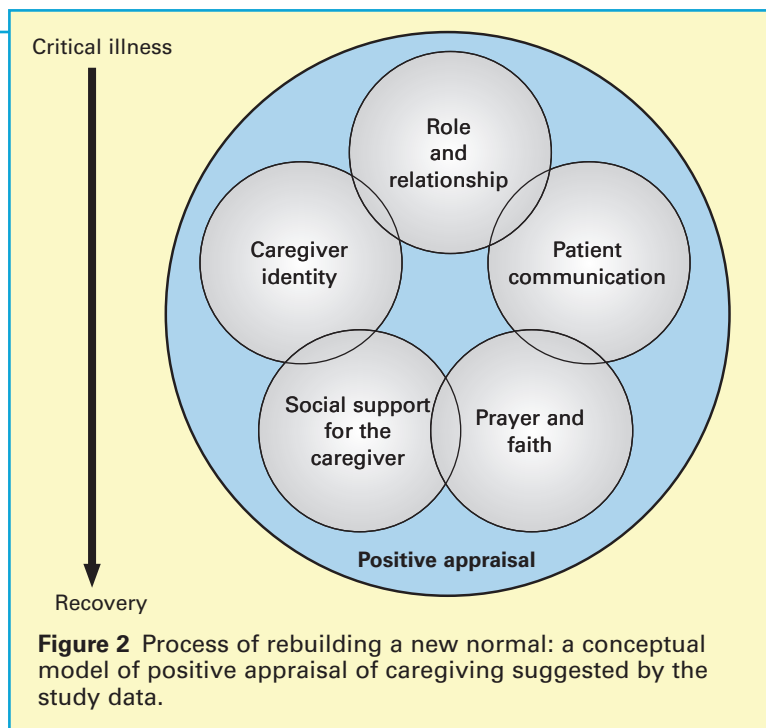
**Table 1**  
**Characteristics of caregiver and patient dyads (n=41)**

Characteristic	Mean (SD)	No. (%) <sup>a</sup>
<b>Caregiver</b>		
Age, y	51.88 (12.22)	
Male sex		10 (24)
White race		38 (93)
Relationship to patient		
Spouse or significant other		23 (56)
Adult child		10 (24)
Parent or sibling		8 (20)
Education, y	14.49 (3.10)	
Working full or part time (yes)		26 (63)
Having religious belief or preference (yes)		33 (80)
Difficulty in paying for needs		
Extremely or somewhat difficult		21 (51)
Not at all difficult		20 (49)
<b>Patient</b>		
Age, y	54.76 (17.18)	
Male sex		28 (68)
White race		38 (93)
ICU admission diagnosis		
Respiratory failure		22 (54)
Sepsis/multisystem failure		8 (20)
Gastrointestinal, hepatic		7 (17)
Others		4 (10)
Charlson Comorbidity Index	3.83 (3.41)	
APACHE II score	21.56 (8.08)	
ICU length of stay, d	24.10 (14.24)	
Days of mechanical ventilation	21.15 (13.55)	
Care needs before ICU admission <sup>b</sup>		
No needs		24 (59)
Moderate needs		7 (17)
High needs		10 (24)

Abbreviations: ADL, activities of daily living; APACHE, Acute Physiology and Chronic Health Evaluation; IADL, instrumental activities of daily living; ICU, intensive care unit.

<sup>a</sup>Because of rounding, percentages may not total 100.

<sup>b</sup>No needs = no impairment in ADL or IADL; moderate needs = more than 1 impairment in IADL, but no impairment in ADL; high needs = at least 1 impairment in ADL.



I tell them that they're their loved one's best advocate, you know, you need to speak up for them. If their voice is weak, then you need to be strong, and I tell them that.

Despite the sudden nature of this disruption, overall, caregivers reported that the critical illness experience led to a greater appreciation of the patient and an improved relationship. The serious nature of the patient's illness created an opportunity to view the relationship in a more positive light, especially when the caregiver was faced with the possibility of losing the patient. Over time, many couples resumed activities that they had enjoyed before the

critical illness. This behavior was viewed as reestablishing the relationship, perhaps as building a "new normal": "We go out some now, you know, back to socializing. So I'd say it's good, almost normal what we had before" (husband,

2 months). Caregivers described a sense of reciprocity, an opportunity to return the care that they had received from the patient in the past or to provide care that might be reciprocated in the future. This concept offset the viewpoint of caregiving as a burden. Children expressed a degree of obligation or duty with the view that the parent had provided care to them in the past and caregiving was an honor and expectation.

**"All my father's done for me all his life, I'm so thankful that I'm able to do that for him."**

*Caregiver Identity.* Many caregivers expressed their view that caring was integral to being a spouse, an adult child, or a sibling. The duty to care was not a burden but fulfillment of a promise:

I've always thought about it [caregiving] as a part of being married. I just naturally assume that, you know, God gives us the ability to live to be old. And we age together, then we need to take care of each other. (Husband, ICU hospitalization)

Others expressed that caring and caregiving were part of who they were as people, seeing themselves as "caring individuals" who derived positive feelings from fulfilling this part of their identity: "And being the type of person that I am, I'm happy to jump in and help any way that I can" (mother, 2 months). In addition, some caregivers described family caregiving as part of the family's identity. Previous caregiving experiences with other family members enabled some families to engage readily with the hospital environment, to work as a unit to support each other, and to expect this behavior as a family norm.

*Patient Communication.* Family caregivers acknowledged patients' lack of communication ability—mainly due to sedation, agitation, and weakness during critical illness—as a barrier to maintaining their roles and relationship. Over time, family caregivers viewed the return of communication as evidence of recovery, allowing progress toward restoring the relationship. In addition, expressions of appreciation from the patient provided the caregivers with some positive feedback about their impact and indicated a return of the reciprocity that was an expectation in the roles: "I am able to speak to him and he is able to talk back to me, and I can make him laugh and I can do something" (mother,  $\leq 2$  weeks).

*Social Support for the Caregiver.* The availability of others improved the appraisal of caregiving. Caregivers described the role of social support in various ways, such as a large network of people, frequent visits from people, or other people actively undertaking some tasks that enabled the caregiver to devote their attention to vigilance in the early stages of critical illness:

We've been given food and we've been given gas cards and that was something I've never thought of to do, when somebody had to make daily trips to [the hospital]. (Wife, ICU hospitalization)

In order to give this new role full attention, caregivers who had a strong social support system



**Table 2**  
**Exemplar quotations from caregivers from ICU**  
**hospitalization to 4 months after ICU discharge**

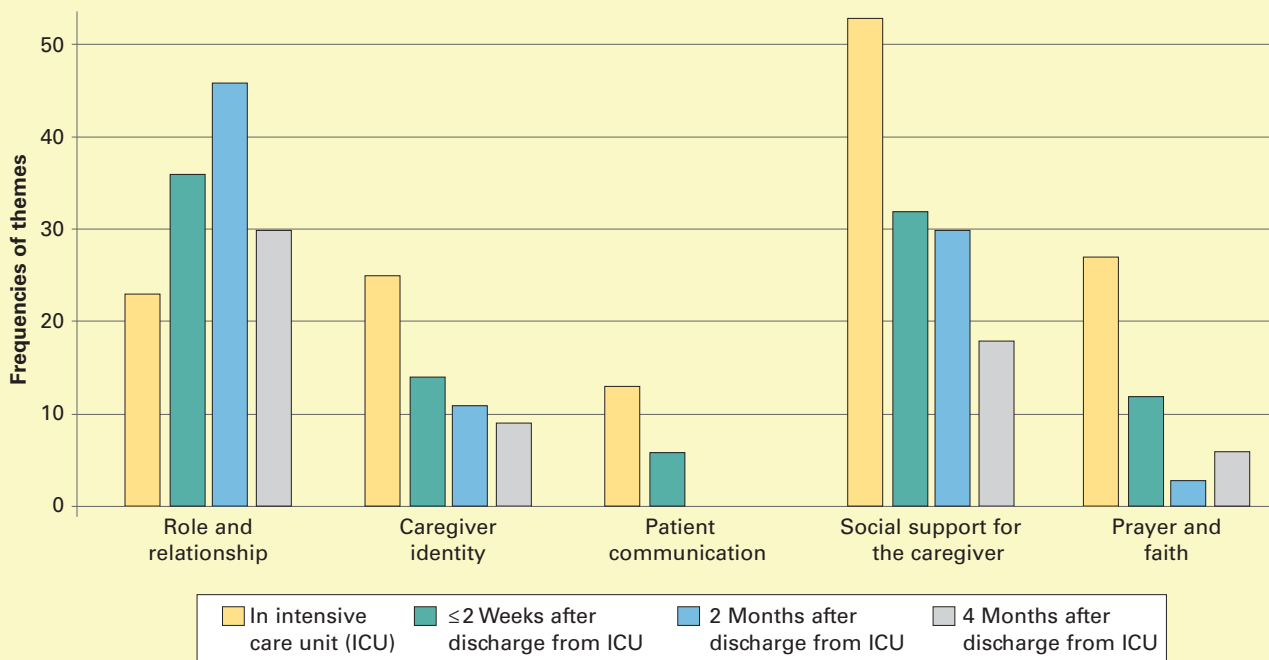
Theme	Data collection time point			
	ICU hospitalization	≤2 Weeks	2 Months	4 Months
Role and relationship	"I feel like I have to be the strong one now and he was always the strong one . . . I have to watch out for him instead of him watching out for me, it's like a role reversal." (Daughter)	"Probably closer, probably appreciate him more—each other more, and maybe don't take things quite so much for granted; things are a little more important now, things we do and say and it just makes you appreciate each other more, I think." (Father)	"We've kind of become like partners again like we were before his illness because he's well enough to participate and think about, you know, the whole family picture and the relationship." (Wife)	"I still do some of the grocery shopping, a little bit that I didn't used to. We share more of the household chores than we used to. I've kind of gotten to the point where I worked and I came home, and did my thing and she had to take care of the house." (Husband)
Caregiver identity	"I'm a caring person. And, especially family members, that love is just so strong that makes it easier." (Wife)	"Something you promised to do when you married them. I've always been a caregiver I guess, you know, we went from baby dolls [laughing] to kids to grandchildren." (Wife)	"There's no doubt in my mind that I would do this because I don't want to see them in a nursing home. That's why I went for my career as it was, because I knew that I had enough knowledge to take care of my elderly parents because I see so many of them get thrown in nursing homes and I didn't want that to be their kind of life." (Daughter)	"I'd do anything for any of my kids. I like doing things for people—I like doing things for people and it makes me happy. I like just seeing a smile come on someone's face when they know I've done something a little extra or done something well for them." (Mother)
Patient communication	"At the moment there's no... relationship, no communication. Um...there's nothing wrong with the relationship, he's just very sick and he doesn't . . . he can't respond at all to anything." (Wife)	"So it's much easier to take care of someone when they can actually talk. You know, put the speaking valve and it makes it 100 times easier to figure out what he wanted and when he needed it." (Wife)	— <sup>a</sup>	— <sup>a</sup>
Social support for the caregiver	"[It] probably means a lot that I can turn to them [friends, family], and you know either cry or you know talk to them or vent or something. And they're there. So yup, I think that's very important." (Parent)	"It helps to form a little pseudo-family type unit where everyone, you know, keeps track of what's going on, and everyone is glad when good things happen, and everyone is sorry when things don't go the right way." (Daughter)	"And I have some really good friends that you know stop down and help out and brought me meals and stuff so I didn't have to make a whole dinner when I got home from work and that's helped out." (Wife)	"We had a lot of that up front when he was in the hospital. We got lots of meals and food and stuff like that, which was very nice. But not too much later." (Wife)
Prayer and faith	"If you have a strong faith and belief that God will bring your family member through, then that's what gets me through; people praying for my dad, you know, I pray for my dad, ministers come and minister to him." (Daughter)	"I never give up hope; I do a lot of praying 'cause I know it's—in my opinion God just took him and helped him heal—healed him and got him out of that." (Father)	"You have to pray. It's not always in your hands, it's, you know, in God's hands." (Daughter)	"Just keep positive. You have to have a positive attitude; you can't lose hope. Because if you start to lose hope, then everything you try to do seems like a struggle. And you just have to keep your faith and hope and a positive attitude and keep moving forward." (Mother)

Abbreviation: ICU, intensive care unit.

<sup>a</sup>Patient communication did not appear as a priority in interviews at 2 and 4 months as the patient's verbal communication returned.

appreciated financial support, triage of information sharing, meals, and presence. Over time, this shared responsibility eventually enabled the caregiver to

resume self-care or reestablish social relationships: "I went and got a perm yesterday, my sister watched my mother" (daughter, ≤2 weeks). For some caregivers,



**Figure 3** Thematic frequencies over time.

this support continued over time; for others, the support decreased over time.

Several caregivers had little social support owing to distance or competing priorities of other family members, yet these caregivers were certain that they could engage their social network when needed. Other families

found this shared experience to be a positive influence as they adjusted to their new roles. During ICU hospitalization, one family debriefed as a group at the end of the day to “compare notes” and make plans for the following day. Another way that family caregivers obtained social support

was through interacting with other families in the waiting room. This social community clarified services, established norms for how to interact with staff, and offered shared experiences.

*Prayer and Faith.* Caregivers acknowledged the importance of prayer and faith. They had faith that the outcome would be good and hope in the future that the patient would return to a healthful state. Many caregivers prayed and appreciated prayers from other family members, friends, or their church. Family members described the importance of prayer and faith across the time points:

We pray a lot. I mean that’s really the way we get through our life when bad things happen. And we pray not just for [name]

but for all the people taking care of him. For their skills, for their brains, for whatever they’re doing for him. That’s hard because you don’t know if you’re praying enough. That’s what I ask everybody to do, just pray. (Wife, ICU hospitalization)

### Thematic Changes Over Time

Themes changed over time, as seen in Figure 3. Changing contexts influenced roles and relationships as the caregivers became more actively involved and responsible for the day-to-day caregiving. One aspect of role was establishing a new normal, a dimension that increased over time. This change may be due to the return to preillness roles and social identity for both the caregiver and the patient. As the patient recovered, some responsibilities lessened as the patient resumed preillness self-care activities. Social support remained an important component of a positive appraisal of caregiving but did lessen over time.

The loss of the patient’s ability to communicate was important during the ICU hospitalization and within 2 weeks after ICU discharge but was no longer a theme as the patients regained their voices. However, as patients regained their voices, they were able to express appreciation, an additional contributor to a positive appraisal of caregiving. The importance of faith and prayer was described most often during ICU hospitalization, when the patient’s condition and prognosis were more tenuous.

“She was afraid she wouldn’t have the stamina but she and I went to the festival and she did great!”

## Discussion

In this qualitative secondary analysis, family caregivers described factors that helped them positively appraise caregiving experience from patients' ICU hospitalization to 4 months after ICU discharge. Our analysis depicted ICU family caregivers' responses from a new and unique angle. In the parent study, the interview questions were not directed exclusively at assessing positive aspects of caregiving, yet most of the caregivers naturally expressed positive appraisals over time. Our findings illustrate how caregivers rebuild a new normal from patients' ICU hospitalization to recovery and what makes caregivers feel positive about their experience during the process.

Although the vast majority of previous research has focused on negative aspects of caregiving—for example, psychological distress and burden—positive aspects of caregiving have been reported in studies with caregivers of people living with other conditions, such as cancer<sup>27</sup> or dementia.<sup>28-30</sup> When we compare our findings with models of positive aspects of caregiving in other caregiver populations,<sup>27,29-34</sup> we acknowledge that caregivers of ICU survivors have some similar characteristics yet have some experiences that are unique. Caregiving for patients with chronic illness is without the traumatic, life-threatening event typically associated with critical illness. There is little expectation of recovery from schizophrenia or dementia, yet a positive recovery trajectory from critical illness is possible. Because of this variability, models of caregiving may be conceptually different for caregivers of ICU survivors.

Given that to date most ICU caregiving research has been focused on the stress and burden of caregiving, inquiry might be directed toward strategies that strengthen the dyadic relationship and perceptions of accomplishment and satisfaction. Our results indicate that there may be value in cognitive restructuring of the caregiving experience, capitalizing on the commitment and sense of purpose. Cognitive restructuring is a component of cognitive-behavioral therapy,<sup>35,36</sup> an intervention that could be tested in family caregivers of ICU survivors. Our data support the ideas of intrinsic reward (fulfilling identity) and extrinsic reward (appreciation from patient) that are echoed in 2 recent models of positive aspects of caregiving in dementia.<sup>29,30</sup> A positive dyadic relationship and feelings of accomplishment in these 2 models were conceptually similar to our findings.

On the other hand, caregiver self-efficacy and skill mastery were important determining factors in models related to dementia caregivers<sup>29,30</sup> and in a

recent model of ICU caregiving presented by Ågård and colleagues.<sup>37</sup> Our participants did not describe the importance of caregiver skill or self-efficacy. Because many patients spent time in other settings (eg, long-term acute care) before returning home, their recovery may not have required the level of caregiving skill noted in other studies. Additional study could determine how caregivers of ICU survivors perceive caregiving self-efficacy and its effects on their relationships, caregiver health and well-being, and resumption of fulfilling activities.

Many caregivers appreciated the information from staff (ie, daily updates on patients' condition and the care from ICU staff) and wished they had known more. They highlighted the importance of the support of friends and families, who shared responsibilities and permitted caregivers to assume their primary role as advocate for the patient. Family caregivers also acknowledged the support they received from other families in the waiting room who shared the "rules of the road" with them. This type of support had importance similar to that of social support, as reported in a recent meta-analysis of ICU family caregiver needs and experiences.<sup>38</sup>

## Clinical and Research Implications

This study has several implications for clinical practice and research. First, ICU staff members should acknowledge the importance of caregivers as a valuable care partner during the acute phase of critical illness. As outlined by several models of caregiving,<sup>37-39</sup> families need information, rapport with ICU staff, and opportunities to maintain their relationship with their family member. Our data suggest that although caregivers appreciate information, social support may play an especially crucial role in developing a positive appraisal of caregiving. Testing of novel interventions to improve social support for caregivers is warranted. Because our caregivers expressed the importance of prayer and faith, offering resources like quiet space could be a simple strategy to meet the spiritual needs of families.

## Limitations

Our study has several limitations. First, we conducted a secondary analysis of qualitative interview data obtained from a convenience sample. Given that positive aspects of caregiving were not the primary focus of the parent study, we analyzed semistructured interviews that longitudinally explored the caregiving experience to determine data adequacy to answer our research questions. The context of the original study cannot be reproduced in a secondary analysis. Although



1 team member was the primary data collector, reflexivity between researchers, families, and setting is restrained.<sup>40</sup> Thematic saturation related to the positive aspects of caregiving cannot be ensured,<sup>41</sup> although the data were rich. Purposive sampling in a larger caregiver sample would have allowed more variation until achieving saturation. Nearly all our respondents were white; thus, our sample lacks diversity. Consequently, we are unable to report racial differences in perceptions of caregiving experiences, as described in the dementia literature.<sup>42,43</sup> Therefore, generalization should be performed with caution.

## Conclusion

Our findings indicate that although it is difficult, family caregivers of ICU survivors can identify positive aspects of their caregiving role. Future studies that prioritize the positive aspects of caregiving for ICU survivors are warranted. As demonstrated in other caregiving populations, interventions that reframe caregiving in a more positive light may enable caregivers to avoid poor physical and mental health outcomes.

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## FINANCIAL DISCLOSURES

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## REFERENCES

1. Esteban A, Frutos-Vivar F, Muriel A, et al. Evolution of mortality over time in patients receiving mechanical ventilation. *Am J Respir Crit Care Med.* 2013;188(2):220-230.
2. Anderson WG, Arnold RM, Angus DC, Bryce CL. Posttraumatic stress and complicated grief in family members of patients in the intensive care unit. *J Gen Intern Med.* 2008;23(11):1871-1876.
3. Azoulay E, Pochard F, Kentish-Barnes N, et al. Risk of post-traumatic stress symptoms in family members of intensive care unit patients. *Am J Respir Crit Care Med.* 2005;171(9):987-994.
4. Cameron JI, Chu LM, Matte A, et al. One-year outcomes in caregivers of critically ill patients. *N Engl J Med.* 2016;374(19):1831-1841.
5. Lemiale V, Kentish-Barnes N, Chaize M, et al. Health-related quality of life in family members of intensive care unit patients. *J Palliat Med.* 2010;13(9):1131-1137.
6. Choi J, Donahoe MP, Zullo TG, Hoffman LA. Caregivers of the chronically critically ill after discharge from the intensive care unit: six months' experience. *Am J Crit Care.* 2011;20(1):12-23.
7. Choi J, Sherwood PR, Schulz R, et al. Patterns of depressive symptoms in caregivers of mechanically ventilated critically ill adults from ICU admission to two months post-ICU discharge: a pilot study. *Crit Care Med.* 2012;40(5):1546-1553.
8. Choi J, Tate JA, Hoffman LA, et al. Fatigue in family caregivers of adult intensive care unit survivors. *J Pain Symptom Manag.* 2014;48(3):353-363.
9. Davidson JE, Jones C, Bienvenu OJ. Family response to critical illness: postintensive care syndrome-family. *Crit Care Med.* 2012;40(2):618-624.
10. Beesley SJ, Hopkins RO, Holt-Lunstad J, et al. Acute physiologic stress and subsequent anxiety among family members of ICU patients. *Crit Care Med.* 2018;46(2):229-235.
11. McAdam JL, Fontaine DK, White DB, Dracup KA, Puntillo KA. Psychological symptoms of family members of high-risk intensive care unit patients. *Am J Crit Care.* 2012;21(6):386-394.
12. Fumis RRL, Ranzani OT, Martins PS, Schettino G. Emotional disorders in pairs of patients and their family members during and after ICU stay. *PLoS One.* 2015;10(1):e0115332. doi:10.1371/journal.pone.0115332
13. Pochard F, Darmon M, Fassier T, et al. Symptoms of anxiety and depression in family members of intensive care unit patients before discharge or death: a prospective multicenter study. *J Crit Care.* 2005;20(1):90-96.
14. Gil-Julíá B, Bernat-Adell MD, Collado-Boira EJ, Molés Julio MP, Ballester-Arnal R. Psychological distress in relatives of critically ill patients: risk and protective factors. *J Health Psychol.* Published online December 23, 2018. doi:10.1177/1359105318817357
15. Cameron JI, Herridge MS, Tansey CM, McAndrews MP, Cheung AM. Well-being in informal caregivers of survivors of acute respiratory distress syndrome. *Crit Care Med.* 2006;34(1):81-86.
16. Ågren S, Strömberg A, Jaarsma T, Luttk MLA. Caregiving tasks and caregiver burden; effects of a psycho-educational intervention in partners of patients with post-operative heart failure. *Heart Lung.* 2015;44(4):270-275.
17. Hamilton M, Tomlinson G, Chu L, et al. Determinants of depressive symptoms at 1 year following ICU discharge in survivors of  $\geq 7$  days of mechanical ventilation: results from the RECOVER program, a secondary analysis of a prospective multicenter cohort study. *Chest.* 2019;156(3):466-476.
18. van Beusekom I, Bakhshi-Raiez F, de Keizer NF, Dongelmans DA, van der Schaaf M. Reported burden on informal caregivers of ICU survivors: a literature review. *Crit Care.* 2016;20(1):16. doi:10.1186/s13054-016-1185-9
19. Van Pelt DC, Milbrandt EB, Qin L, et al. Informal caregiver burden among survivors of prolonged mechanical ventilation. *Am J Respir Crit Care Med.* 2007;175(2):167-173.
20. Choi J, Hoffman LA, Schulz R, et al. Health risk behaviors in family caregivers during patients' stay in intensive care units: a pilot analysis. *Am J Crit Care.* 2013;22(1):41-45.
21. Choi J, Tate JA. Risk of post-traumatic stress disorder in family caregivers of neuroscience intensive care unit patients. *J Emerg Crit Care Med.* 2018;27:5. doi:10.21037/jccm.2018.09.04
22. Choi J, Hoffman LA, Schulz R, et al. Self-reported physical symptoms in intensive care unit (ICU) survivors: pilot exploration over four months post-ICU discharge. *J Pain Symptom Manag.* 2014;47(2):257-270.
23. Choi J, Lingler JH, Donahoe MP, Happ MB, Hoffman LA, Tate JA. Home discharge following critical illness: a qualitative analysis of family caregiver experience. *Heart Lung.* 2018;47(4):401-407.
24. Bengtsson M. How to plan and perform a qualitative study using content analysis. *NursingPlus Open.* 2016;2:8-14.
25. Mills AJ, Durepos G, Wiebe E, eds. *Encyclopedia of Case Study Research: L-Z; index.* Vol 1. Sage Publications; 2010.
26. Creswell J, Poth C. *Qualitative Inquiry and Research Design: Choosing Among Five Approaches.* Sage Publications; 2018.
27. Li Q, Loke AY. The positive aspects of caregiving for cancer patients: a critical review of the literature and directions for future research. *Psychooncology.* 2013;22(11):2399-2407.
28. Cohen CA, Colantonio A, Vernich L. Positive aspects of caregiving: rounding out the caregiver experience. *Int J Geriatr Psychiatry.* 2002;17(2):184-188.
29. Carboneau H, Caron C, Desrosiers J. Development of a conceptual framework of positive aspects of caregiving in dementia. *Dementia.* 2010;9(3):327-353.
30. Cheng ST, Mak EPM, Lau RWL, Ng NSS, Lam LCW. Voices of Alzheimer caregivers on positive aspects of caregiving. *Gerontologist.* 2016;56(3):451-460.
31. Corman MK. The positives of caregiving: mothers' experiences caregiving for a child with autism. *Fam Soc.* 2009;90(4):439-445.

32. Kayfitz AD, Gragg MN, Orr RR. Positive experiences of mothers and fathers of children with autism. *J Appl Res Intellect Disabil*. 2010;23(4):337-343.
33. Kulhara P, Kate N, Grover S, Nehra R. Positive aspects of caregiving in schizophrenia: a review. *World J Psychiatry*. 2012;2(3):43-48.
34. Mackenzie A, Greenwood N. Positive experiences of caregiving in stroke: a systematic review. *Disabil Rehabil*. 2012; 34(17):1413-1422.
35. Dobson KS, Dozois DJ. *Historical and Philosophical Bases of the Cognitive-Behavioral Therapies*. Guilford Press; 2010.
36. Beck J. *Cognitive Behavior Therapy: Basics and Beyond*. 2nd ed. Guilford Press; 2011.
37. Ågård AS, Egerod I, Tønnesen E, Lomborg K. From spouse to caregiver and back: a grounded theory study of post-intensive care unit spousal caregiving. *J Adv Nurs*. 2015; 71(8):1892-1903.
38. Linnarsson JR, Bubini J, Perseus KI. A meta-synthesis of qualitative research into needs and experiences of significant others to critically ill or injured patients. *J Clin Nurs*. 2010;19(21-22):3102-3111.
39. Davidson JE, Mendis JM, Huynh TG, et al. Family-centered care interventions to minimize family intensive care unit syndrome and post-intensive care syndrome-family. In: Netzer G, ed. *Families in the Intensive Care Unit*. Springer; 2018:187-215.
40. Tate JA, Happ MB. Qualitative secondary analysis: a case exemplar. *J Ped Health Care*. 2018;32(3):308-312.
41. Heaton J. *Reworking Qualitative Data*. Sage Publications; 2004.
42. Roff LL, Burgio LD, Gitlin L, Nichols L, Chaplin W, Hardin JM. Positive aspects of Alzheimer's caregiving: the role of race. *J Gerontol B Psychol Sci Soc Sci*. 2004;59(4):P185-P190.
43. Roth DL, Dilworth-Anderson P, Huang J, Gross AL, Gitlin LN. Positive aspects of family caregiving for dementia: differential item functioning by race. *J Gerontol B Psychol Sci Soc Sci*. 2015;70(6):813-819.

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