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Improving Post-Injury Care: Key Family Caregiver Perspectives of Critical Illness After Injury

BACKGROUND: There is little research about how caregiver experiences evolve from ICU admission to patient recovery, especially among caregivers for patients who have traumatic injuries. In this study, we characterize diverse caregiver experiences during and after ICU admission for injury.

METHODS: This prospective observational study is based in a level 1 trauma center in Philadelphia, Pennsylvania. Longitudinal interviews among caregivers of patients who required ICU admission for traumatic injury were conducted from the time of ICU admission to 12 months after hospital discharge. Transcripts were analyzed using a qualitative descriptive approach.

RESULTS: Sixty-five interviews were conducted with 19 caregivers. The interview results converged on four areas: experiences in the ICU, the aftermath of violent traumatic injury, caregiver responsibilities, and care in the context of the wider family. In the ICU, caregivers contended with worry and uncertainty, and they often hid these feelings. Many felt that they always needed to be at the bedside, leading to stress and exhaustion. Caregivers had difficulty communicating with their loved ones, and communication itself sometimes became a source of conflict. Over time, caregivers were burdened by many managerial responsibilities. In addition, violent traumatic injury caused an overlay of concern for patients' safety. The need to plan for recovery caused caregivers to make substantial sacrifices. As a result of these difficult experiences, some caregivers and patients drew closer together, while others were divided by conflict.

CONCLUSIONS: Illness after traumatic injury may be devastating for caregivers, disrupting emotional wellbeing and other aspects of life. Caregivers are variably prepared for the challenges of ICU care and caregiving through convalescence and require robust support during and after ICU admission to enable effective communication, resource access, and an ongoing relationship with the healthcare team.

KEY WORDS: caregivers; critical care; family; injury; Post-Intensive Care Syndrome-Family; qualitative study

Critical illness or injury introduces uncertainty, stress, and conflict for patients and family members alike as they work together toward goals of care, end-of-life discussions, and major adjustments in life circumstance (1). Family members are often ill prepared to serve as surrogate decision-makers for patients who are unable to chart the course of their own care (2). These dynamics also permeate the post-hospital period for ICU survivors and their families.

The outcomes of ICU caregivers and families have been partially explored in the research on Post-Intensive Care Syndrome-Family (PICS-F) that focuses on the emotional experience of caregiving. Despite increasing attention, the risk factors for PICS-F remain incompletely understood. Some studies address economics, education, age, health status, and index hospitalization illness, but few

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focus on the family or caregiver experience during the post-hospitalization recovery phase, especially among patients who are critically injured (3–8). Serious traumatic injuries in particular can have enormous effects on the wellness of patients and their caregivers long after an ICU stay, but the context of trauma is underrepresented in studies that examine survivorship (9–11). There is also sparse information overall, and especially for trauma patients, on how caregiver experiences evolve over time.

This study adds to the developing but critical corpus of research that focuses on caregiver experiences associated with ICU survivorship. Qualitative research includes patient and family voices without compromising the rigor or validity of research and provide nuanced views of the changing social realities (12). Open-ended approaches accommodate empirical surprise without overdetermining the domains of importance for patients and families (13). A handful of qualitative studies conducted in Denmark, Saudi Arabia, Hong Kong, Ireland, and Sweden that describe caregiver experiences used variety of parameters for recruitment and time to interview; these usually involved a single interview (3–8). United States and Canada-based research in this area are focused on experiences of caring for patients with specific ICU-treated pathologies such as acute respiratory distress syndrome and sepsis (14, 15) or include a mixed ICU patient population (16, 17). These studies indicate that caregivers of ICU patients experience some common challenges, such as managing uncertainty, maintaining proximity to the patient, and coping with different responsibilities. Although some familial/social factors and conditions in ICUs have been shown to predict PICS-F (such as high-intensity emotions or sleep deprivation) (18), patient diagnoses play an important role in contextualizing and determining caregiver experience.

In this exploratory study, we characterize a range of caregiver experiences spanning critical care through long-term recovery after injury. The interviews conducted with these caregivers were targeted at discovering key elements of the phases and transitions following critical care into recovery to identify essential resources that enable family and caregiver success.

MATERIALS AND METHODS

This prospective longitudinal observational qualitative research project represents one part of a larger

observational cohort study (19) that had a convergent mixed methods design (20) and incorporated the experience of patients and caregivers. Patient-caregiver dyads were recruited from a trauma ICU in an urban level 1 trauma center from March 2016 to November 2016 and followed through November 2017. Study visits occurred across the care continuum: in the ICU (baseline and setback visits), on the inpatient step-down and general floors, at inpatient rehabilitation facilities, and in patients' homes. The research protocol was reviewed and approved by the Institutional Review Board of the University of Pennsylvania (Number 823554). Our report of findings is guided by the Consolidated criteria for Reporting Qualitative research checklist (21).

Study Participants, Recruitment, and Follow-Up

Caregivers were eligible if they self-identified as having a close relationship with the patient who was 1) greater than 18 years old, 2) sustained an injury requiring ICU care, 3) mechanically ventilated for greater than or equal to 24 hours, 4) ICU length of stay greater than 48 hours, and 5) able to speak English. Caregivers were greater than 18 years old and were English speaking. Family members of patients under the care of the principal investigator and patients in police custody at the time of screening were not approached for participation to avoid potential coercion. We used purposive sampling (22), aiming to achieve representation across four strata believed to influence post-injury recovery: age (< 50 vs 50+ yr), gender, race/ethnicity, and mechanism of injury (blunt vs penetrating) (23–27). We specified a target sample size of 12–15 dyads based on data supporting this size as sufficient to reach thematic or theoretical saturation (28, 29). Patients were screened for eligibility every business day during the recruitment period. Bedside staff of potentially eligible patients were queried about suitability of the dyad for participation, at which point the caregiver was approached and invited to join the study. Written informed consent was obtained from caregivers for their own and the patient's participation. Once patients regained consciousness, they were reconsented.

Data Collection

A patient-designated caregiver was multiply interviewed over the year following the patient's injury and

index hospital discharge using a semi-structured interview guide (see **Supplemental Material**, <http://links.lww.com/CCX/A979>). Patients experiencing a setback (e.g., ICU readmissions) had an additional “setback” study visit. Interview scripts were developed based on a systematic review of the PICS and PICS-F literature (30) as well as consultation with the Patient and Family Advisory Council of the Hospital of the University of Pennsylvania. The interview guides were pilot-tested for feasibility, acceptability, and construct clarity with two family-caregiver dyads and subsequently edited. The guides were iteratively adapted throughout data collection to clarify emerging questions and explore themes identified in early analysis.

All interviews were conducted by research assistants with diverse gender, racial, and ethnic identities. When possible, the same interviewer was used for each participant over successive sessions. A baseline visit occurred during the patient’s initial ICU admission and included caregiver participants. Post-ICU discharge contact included a patient interview, a separate caregiver interview, and a dyadic interview including both the patient and caregiver. Interviews were audio recorded and professionally transcribed. Participants were compensated U.S.\$30 per interview visit.

Analysis

Data analysis focused on caregiver views and perspectives of their own experiences rather than information addressing the patient. One member of the research team (A.R.P.) coded interview data by hand once with a deductive thematic approach (31) in order to identify broad topics that answer the research question. After description of themes, interviews were reviewed again and descriptively analyzed with an aim to represent subjective and constructed meanings of experience utilizing inductive reasoning (32–34). The principal investigator (M.L.-F.) cross-checked emergent themes and meanings to confirm consonance with the findings from the main study.

RESULTS

Nineteen patient-caregiver dyads were enrolled, and 13 completed the study. Of the six who did not complete the study, two withdrew due to feelings of overwhelm, one withdrew because they relocated out of the region, two patients died, and one dyad was lost

to follow-up. We conducted a total of 65 caregiver interviews. Those who completed the study included seven mothers, three wives, one father, one neighbor, and one fiancé; only one caregiver was not a family member. All but one of the caregivers were women; additional caregiver demographics were not collected. Patient demographics from the parent study are provided in Supplemental Material (<http://links.lww.com/CCX/A979>).

In the ICU: Helplessness, Lack of Control, Uncertainty, and Communication Challenges

At the hospital, caregivers experienced feelings of helplessness and lack of control, even when they trusted the medical team. As families waited for medical updates, they contended with uncertainty: “every minute was like agony because you just didn’t know” (Participant 11). They worried that the patient’s medical status might worsen at any moment. The symptoms associated with patients’ injuries felt scary. For example, one patient’s brain injury caused a visual field neglect, which was frightening for the caregiver to observe. Seeing a patient restrained or unable to speak was also stressful. “It’s just hard to see him like that in the hospital. Like when I look at our pictures, it just gets me emotional, because I’m not used to seeing him like that at all” (Participant 2). Some caregivers described feeling the patient’s pain themselves. Caregivers felt tremendous sadness from the pain they perceived their loved one was suffering. “I go in the shower, and I cry, so I just don’t want him to see it” (Participant 13). Some caregivers had nightmares immediately after discharge and others experienced stress and worry lasting many months. One caregiver described his preexisting mental health problems worsening and having to increase his medication doses.

These feelings were compounded by exhaustion due to stress and poor sleep. While caregivers described that it was difficult to sit in the hospital all day, they sometimes preferred to be present at the bedside rather than stay at home and worry from afar. Traveling to the hospital required substantial coordination among families and caregivers, including planning for food, personal hygiene, and homemaking. A 1:1 staff observer made one caregiver feel more secure about leaving to take care of their own needs.

Communication was particularly problematic when patients were intubated, and this challenge added further uncertainty as caregivers wondered how their

loved ones felt. For example, one participant stated: “There’s been something he’s been trying to tell us for days now, we just can’t figure it out” (Participant 10). Caregivers reported that they did not know how the patient was feeling and what they might need. For example, one patient spent 2 hours trying to communicate that she needed a blanket, and her caregiver described feeling saddened by the patient’s frustration and anger. Another caregiver lamented that she could not talk to her husband in private because he was not able to pick up the phone, so a staff member always had to hold it for him.

Beyond mechanical communication difficulty, caregivers were uncertain about what they should be telling the patient and other family members. For example, one caregiver felt conflicted between alerting the patient to her presence but also did not want to communicate “something being wrong” (Participant 11). Families had conflicts about what topics should be discussed in front of the patient, and some worried that talking about the injury would be hurtful to the patient. Caregivers sometimes felt that they did not know the patient’s status or treatment plan. When they did, some still had difficulty keeping everyone updated on new information. Others experienced challenges in talking to children in ways that were both truthful and developmentally appropriate. Some wondered whether it was appropriate to bring young children into the hospital to visit their injured family member. Children expressed fear and anger, and some began exhibiting behavioral issues.

The Aftermath of Violent Traumatic Injury

Four patients in the study group sustained violent traumatic injury. Caregivers of these patients worried about similar events occurring to them or other loved ones in the future, “you can never think somebody’s safe” (Participant 1). Caregivers reported feelings of anxiety, intrusive worrying, and nightmares about events, “I get afraid, I don’t know why.” One participant whose son had been injured by a gunshot wound compared her experience to post-traumatic stress disorder, stating:

whoever did his to him, they did it to me... even when I was here [at the hospital] and I was trying to smoke outside, I was always thinking that maybe somebody gonna shoot me.... I was like, that kind of paranoid because if that

happened for no reason, that could happen to anybody anyway (Participant 2, 6 months after admission).

This same participant expressed worry about her son’s safety as he returned to the same street where he was shot. These feelings of fear and worry related to at-home recovery for patients who were hospitalized after violent injury sometimes lasted far after ICU discharge.

Caregiver Responsibilities and Sacrifices

Caregivers described many responsibilities during and after the ICU, which are summarized in **Table 1**. These various responsibilities caused stress and exhaustion. As caregivers adopted new responsibilities over time, some struggled to reconcile themselves to the reality that their loved ones would not recover quickly.

Caregiver and the Wider Family Unit: Closer or Farther Apart

Caregivers discussed their role in the larger context of the patient’s family. Families varied in how they supported each other through critical injury and recovery. Families sometimes had conflicts about how they should care for the patient. For example, one caregiver felt that she should oversee the patient’s care while other members of the family labeled her as a “control freak” (Participant 1). Differing expectations about what it meant to support the patient led to conflict. For example, one patient’s family criticized his caregiver for treating him as a healthcare worker would a patient, rather than “as his girlfriend” (Participant 13). Caregivers shared frustration with patients when patients became angry about their injury and refused to participate in recovery activities, and they sometimes disagreed about how much or what kind of help the patient required. Taking care of the patient was sometimes disruptive to family caregivers, “I feel like if there is a lot more commotion... probably a lot more emotional stress” (Participant 11). Intensive time spent with each other put strain on relationships, causing additional stress and frustration, even when family members were appreciative to be present with one another (Participant 17).

Relationships among patients and their caregivers changed in vastly different and sometimes unpredictable ways. Some families became an outlet for the

TABLE 1.
Caregiver Responsibilities and Sacrifices

Theme	Details and Examples	Caregiver Perspectives
Responsibilities	<p>Hands-on: Feeding and toileting, accompaniment to appointments, advocacy</p> <p>Financial: Healthcare financial obligations, negotiating with insurers and employers</p> <p>Accessibility: Renovating or moving homes to accommodate new functional limitations</p> <p>Existing obligations: Work, attending to other family members</p>	<p>Caregivers worried that something might go wrong. When Participant 14 checked on the patient (her neighbor), she found her asleep with the door unlocked and stove burner on. Many worried about the patient's ability to care for themselves when they weren't present, "it was scary to bring him home broken" (Participant 8). This led to feelings of overwhelm: "keeping the balls in the air" (Participant 8). Many experienced fatigue, describing their responsibilities as "wearing on me" and having "low periods," "it's been long days." The feeling of being overwhelmed led to stress, "the pressure... it's all in my chest" (Participant 6). Some worried about losing their jobs. "I gotta maintain my income" (Participant 4).</p>
Making sacrifices	<p>Workplace sacrifices: One caregiver relinquished her job, not only because of the time she spent in her caregiver role, but also because she "couldn't focus" (Participant 4).</p> <p>Deferring their own health maintenance: Caregivers delayed their own health needs because they were "more focused on [the patient], not myself" (Participant 17).</p> <p>Foregoing activities: One participant had to forego a family vacation. Another stepped down from her leadership role in the church community.</p>	<p>It was difficult for caregivers to engage in shared coping activities (such as going to religious services or on vacation) since "everything is on hold" (Participant 4). For one family, having an external home health aide helped to relieve the pressure they were experiencing. Nonetheless, caregivers felt beholden to ensuring the patient's wellbeing, "I feel it's your obligation to do what you need to do to make that person comfortable" (Participant 14). "I feel like sometimes I've been going backwards, having a child again to take care of" (Participant 7). While this mother expressed anger, she did not want her child to know that care felt like a burden.</p>

patient to express negative emotions, and one reported that the patient blamed them for medical interventions that were unpleasant and for enforcing strict activity limits. Patients and families sometimes had very different expectations of what it meant to support the patient through recovery. For example, a caregiver might prioritize completing practical tasks while a patient feels that she needs compassion and empathy, "sometimes I just feel like I need that tender loving care a little bit more" (Participant 4). Caregivers struggled with setting boundaries with the patient about their role (e.g., one caregiver wanted to help the patients with daily activities but did not feel comfortable going out to buy the patient cigarettes). Another caregiver described how difficult it was to lose the patient as her primary support person as she struggled to cope with his injury. Existing relationship tensions sometimes worsened, and sacrifices led to resentments, especially when caregivers felt that their efforts were not appreciated. Some patients withdrew from social interactions with the family. Families needed additional support

in navigating these relational changes, such as counseling "so that we can make sure that the relationship does not become so strained that I'm not able to take care of him and he's not able to be a husband to me" (Participant 4).

On the other hand, the difficult experiences of the incident and recovery sometimes brought the patients and their families closer together, "he's more family-oriented than he was, and he understands that he can't—he doesn't need to deal with things on his own" (Participant 8). Many found it meaningful to be together, "we talk more" (Participant 8; Participant 18) and felt more present in their relationships. "We got a lot closer, and our communication has definitely increased" (Participant 15). Members of the family had the opportunity to learn about each other in a new context. "I've learned to become more caring and more understanding..." (Participant 4). Others shared a desire for things to return to their "normal," and found joy in witnessing recovery in small step together. Many shared reliance on a faith, which helped to assuage

worry and strengthened family bonds. “I look at things that would have really been really stressful and now I look at them as opportunities” (Participant 11). Families felt gratitude that their loved one had survived a critical injury, while patients felt grateful for family care, which both transformed into a broader appreciation for one another. For some families, both negative and positive experiences with family relationships precipitated from the critical illness events.

DISCUSSION

This study illustrated some of the salient experiences of caregivers of injured patients throughout ICU care and recovery. Similar to prior studies of families of critically ill patients, caregivers contended with worry and uncertainty while at the bedside and at home, and made decisions that sometimes adversely influenced their health (16, 17). The tension between meeting existing obligations and remaining present at the bedside for comfort and decision-making commonly generated frustration, guilt, anxiety, and stress (14, 15). Our study extends these findings by illuminating how those sentiments expand into the postdischarge phase and are initiated by different stressors. On a broader level, these results encourage reconceptualization of an ICU stay as an event within the context of a life course or life world. Clearly, the vulnerabilities and strengths that patients and their caregivers bring with them can have an enormous impact on their experiences of a critical injury, acute hospitalization, and long-term recovery process. Given the multidimensional nature of the caregiver experience—the majority of which were deleterious—concepts that describe the long-term psychosocial sequelae of hospitalization and critical illness for families and caregivers such as “medical trauma” and “caregiver burden” appear inadequate.

Unsurprisingly, caregivers developed anxiety, intrusive worrying, and disordered sleep (including nightmares) regarding both unintentional injury and intentional injury. Drivers of these issues for caregivers—most of whom are anticipated to be family members or significant others—adds specificity about causation to the PICS-F framework. Accordingly, these data help inform clinicians of the spectrum of stressors that caregivers may perceive and need to manage, all of which may underpin conflict within the ICU or clinic (1). The psychological sequelae described by the PICS-F

model are often conceptualized in direct relationship to the conditions of the ICU and acute inpatient care clinical interventions (35). Our data underscore the need for post-ICU care that addresses caregiver concerns during the patient’s recovery phase, such as dedicated post-ICU clinics and robust at-home care services (36, 37). Despite recent attention focused on the “financial toxicity” related to high cost, complex and multiple-episode care such as oncology management, the sequelae of injury care are more broadly encompassing (38–40). Both intentional and unintentional injury engenders concerns regarding recurrence, environmental safety, and social context for patients and, as our study delineates, caregivers.

This study indicates a need for a family-centered approach to care and support systems for families as well as patients (37) and highlights some areas where interventions may be useful, such as ICU facility design that supports caregiver presence at the bedside and sleep (41) and prioritizing patient-family and patient-caregiver communication. Peer support may also be beneficial in helping caregivers to know what to expect (42). Robust research on interventions aimed toward mitigating the psychologic sequelae of ICU stay for families is extremely limited (43). With increasing numbers of patients surviving critical injury, more patient- and caregiver-partnered research is needed to study the effectiveness and implementation of interventions aimed toward helping families of patients who have experienced traumatic injury (44, 45). Future studies on the psychology of injury might focus on the interactions of traumatic injury and hospital traumas. Future studies might also explore how the desire for hospital visitation is at odds with severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2) infection control policies, which had not come into being at the time of the data collection.

This study contains several limitations as well as strengths. We included a relatively small number of participants cared for in a single trauma center. Accordingly, the unique caregiver experiences and the antecedent injuries that brought patients to the trauma center may not be representative of other centers or their patients and caregivers. Nonetheless, the thematic saturation noted despite different mechanisms of injury suggests a few common groupings of caregiver experience that may provide a framework within which such experiences may be explored. Since we interviewed

only one caregiver per patient, we may not have captured the texture of a more complex multi-individual support system when present. Our study duration of 12 months may have limited our appreciation of the long-term implications of recovery and its impacts on caregiver and patient relationships. Furthermore, our data was acquired before the SARS-CoV-2 pandemic and the important influences that public health measures, social isolation, travel restriction, and universal masking is not reflected in caregiver experiences. Given the wide range of PICS-F impacts, we did not assess family finances or employment status, instead focusing on how caregivers perceived injury and recovery phase care influenced their lives. Future studies with more participants may find it valuable to stratify or further examine caregiver perspectives across income level, gender, age, ethnicity, or varied geographic locations. An important strength, however, is the longitudinal nature of the study, which helped to develop an understanding of how caregiver experiences evolve over time. Another strength is our focus on trauma, since there is sparse information about the experiences of families who are supporting traumatically injured patients.

CONCLUSIONS

This study provides an in-depth, longitudinal, and relational view of caregiver perspectives of ICU stay and recovery in the setting of traumatic injury. Lessons learned from this study include the following: caregivers experience tremendous hardship when a loved one is critically injured, and much more support is needed not only in the acute phase but also as families transition into recovery. Family relationships sometimes change in dramatic and unpredictable ways as caregivers and patients cope with psychologically distressing and stressful experiences. Antecedent violent traumatic injury has a unique overlay as patients and caregivers prepare for the future together. Understanding and implementing long-term support for families will be critical amidst the larger context of COVID-19, an aging population, and increasing numbers of patients surviving intensive care.

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