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Not “Out of Sight, Out of Mind”: Interventions to Relieve Suffering for Bereaved Families After an ICU Death*

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Bereaved family members of ICU decedents suffer from a high burden of emotional and psychologic distress when a loved one dies. The burden can be especially high for family members who participated in end-of-life decisions (1–5). Complicated grief is five-fold higher in bereaved families of patients who die in the ICU compared with the general population (6), and anxiety, depression, and post-traumatic stress disorder (PTSD) symptoms affect 30–50% of bereaved family members months and even years following the loss of their loved one (7). A 2010 Task Force from the Society of Critical Care Medicine proposed the term “postintensive care syndrome-family” (PICS-F) to describe these persistent symptoms (8).

*See also p. 35.

Key Words: bereavement; family members; postintensive care syndrome-family; storytelling

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To date, interventions to improve outcomes for bereaved ICU families have primarily been tested prior to or during ICU admission. Interventions such as preparation of advanced directives, informational brochures, improving communication with the ICU team, and providing additional support with palliative care specialists and structured family meetings during the ICU admission are associated with reduced anxiety, depression, and PTSD symptoms up to 6 months after a loved one dies (9–11). Unfortunately, the overall impact of these interventions has been relatively modest.

Few interventions have targeted bereavement support for surrogate decision makers (SDMs) after an ICU death. This may be due, in part, to theoretic concerns about exacerbating psychologic distress. However, families/SDMs from a multicenter French study identified several positive aspects about bereavement research participation. Bereaved families valued the opportunity to express themselves in a safe space, felt it could offset feelings of abandonment and reinforced that their suffering mattered, even after their loved one died (12).

We were, therefore, delighted to see the study by Barnato et al (13) in this issue of *Critical Care Medicine*. The investigators determined feasibility of a structured storytelling intervention for bereaved SDMs who participated in end-of-life ICU decisions. The storytelling intervention was delivered in person or by telephone by one of two trained social workers 4 weeks following the patient’s death. The social workers received structured training eliciting SDMs’ stories surrounding their ICU experiences, including end-of-life decision making. The enhanced control arm received a condolence letter, a newsletter about grief, and information about grief support services 1 week following the death along with an invitation to participate in storytelling after 6 months. The primary outcomes were feasibility and acceptability of the storytelling intervention based on SDM participants’ feedback, and tolerability measured by the number of mental health referrals. Secondary outcomes included frequency of PICS-F, defined using previously validated cutoffs for symptoms of complicated grief, anxiety,

depression, and PTSD. Individuals who declined participation in the trial were retained as an observation group and completed the same symptom scales for PICS-F at 6 months.

The storytelling intervention for bereaved ICU SDMs met or exceeded the investigators' a priori benchmarks for feasibility, acceptability, and tolerability. They recruited more than 60% of eligible SDMs, and 94% of participants in the storytelling arm reported feeling "better" or "much better" at the end of the study period compared with 69% of controls. Both groups had high symptom burden at baseline that subsided with time. The storytelling group had lower composite scores for PICS-F at the conclusion of the study, although small sample size precluded making inferences about efficacy.

Storytelling interventions may create a natural and comfortable environment for sharing information and allow SDMs to reshape their perspectives when dealing with disturbing and potentially destabilizing life events (14). Storytelling can provide a strategy of making sense of and coming to terms with a traumatic event (15, 16). After a loss or other traumatic experience, narrative interventions have been associated with fewer illness-related physician visits and improved subjective health in studies of college students and Holocaust survivors (17–20).

There are important limitations to consider before attempting to implement storytelling interventions for bereaved SDMs from the ICU. The primary limitation is that this was a pilot feasibility intervention trial. Further research is required to evaluate the efficacy of storytelling interventions in a large, ethnically diverse study population. Only one of the 53 SDM participants self identified as black or African-American. Prior studies have highlighted unique differences in advance care planning between African-American and Caucasian SDMs, raising the question of whether this intervention would have the same impact across ethnically diverse populations (21). It was also not possible to elucidate whether it was the storytelling intervention, itself, that explained differences in PICS-F at 6 months. SDMs allocated to the storytelling intervention also received care and attention from study staff that may alone have translated to improved PICS-F outcomes. In addition, participation in the storytelling intervention may have provided SDMs with a sense of altruistic satisfaction that could have reduced the burden of symptoms. Alternatively, although participants allocated to the enhanced control group received bereavement support through pamphlets and support groups, they were discouraged from storytelling during their participation. This may have contributed to participants in the control group reporting greater distress in answering questionnaires about their PICS-F symptoms. Finally, SDMs who may be in greatest need of help to relieve their psychologic suffering may not be receptive or responsive to a storytelling intervention. These findings may be reflected in the current study as prospective study participants who declined participation in the storytelling intervention, had the highest symptom burden at 6 months.

The recent recognition of the importance of PICS-F should raise additional concern about the psychologic well-being of

family members after their loved ones die in the ICU. This study points to an exciting and potentially feasible storytelling intervention to improve psychologic health in this vulnerable population. If subsequently shown to be effective, a storytelling intervention may improve outcomes in bereaved families and reassure ICU clinicians that the bereaved family's loss is not compounded by additional psychologic suffering in the months and years following their ICU stay.

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What Are the Long-Term Outcomes After Acute, Severe Kidney Injury and What Should We Be Doing About Them?*

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The kidney is a barometer of the severity of critical illness in an individual patient. In this context, the risk of developing clinically significant renal impairment (acute kidney injury [AKI]) is related to the patient's renal physiological reserve and the severity of the systemic illness (1).

The physiological reserve can be inferred based upon age-related loss and disease-related loss (severity and duration), most commonly hypertension and diabetes mellitus. Chronic renal impairment (or disease, chronic kidney disease [CKD]), which is synonymous with a significantly reduced renal physiological reserve, is best defined based upon a combination of a functional measure, most commonly estimated glomerular filtration rate (eGFR) and a measure of damage, most commonly urinary albumin-to-creatinine ratio (ACR) (2). Depending upon the underlying cause and the presence and severity of complications and comorbidities, CKD may progress over months to years, to end-stage renal disease (ESRD) (3). However, interventions that treat the underlying cause, and/or modify the complications/comorbidities, can slow down or even arrest this progression (4).

Although CKD predisposes to AKI, severe AKI, in the context or absence of CKD, can result in, or cause accelerated progression of, CKD (5).

The analogy of the kidney as a critical illness severity barometer is reinforced by the association of an AKI with an increase in the risk of all-cause, acute episode mortality; the magnitude of the risk being proportional to the severity of the AKI. There is a similar association between ESRD and all-cause mortality. The reasons for these associations relate to

the emerging appreciation of acute and chronic, organ cross talk (6). After all, these associations persist despite the widespread availability of renal replacement therapies (RRTs). RRTs are undoubtedly effective in reversing fluid overload, clearing small molecules, and normalizing electrolytes and pH. However, considerable controversy persists regarding RRT including thresholds for/timing of initiation, optimal modality and dose, and immediate risks and benefits. There are considerable costs, both personal and financial, of both acute and chronic RRT; hence, making rational decisions based upon reliable prognostic data are highly desirable though currently elusive.

In this issue of *Critical Care Medicine*, An et al (7) published a retrospective, observational study of the long-term, renal and mortality outcomes of a cohort of 1,764 patients who received RRT during their acute critical illness between 2009 and 2013. At 3 months postinitiation of RRT, only 32% of the cohort was alive. This compares to historical rates of 40%; however, these have been improving with more recent studies that report 3-month survival rates of ~ 55% (8).

The authors identified 331 of 462 survivors with renal function data preceding their acute illness and at 3 months postinitiation of RRT. I have reproduced the renal outcome at 3-month data in **Table 1**. This demonstrates that ~ 65% of patients with baseline CKD stages 1–4 had either returned to baseline function or had suffered less than 35% reduction in eGFR. Though small in numbers, this compares with only 13% of the patients with a baseline CKD stage 5. Over a median further follow-up period of 19 months from initiation of RRT, a small but significant proportion of patients suffered further CKD progression, some to ESRD. The risk of deterioration was markedly greater than CKD three patients receiving long-term surveillance. The authors then compared these long-term outcomes of their cohort to baseline CKD matched individuals. They found that if a patient had developed an AKI requiring RRT and their renal function had deteriorated by greater than 35% (decrease in eGFR), their risk of progressing to ESRD was 250× that of matched controls. If the patient had developed an AKI requiring RRT and their renal function had not deteriorated by greater than 35% (decrease in eGFR), their risk of progressing to ESRD was 14× that of matched controls. Those patients, who had suffered a progression in their CKD at 3 months, had a 2× increased risk of all-cause mortality compared with those that had not.

*See also p. 47.

Key Words: acute kidney injury; continuous renal replacement therapy; long-term outcome; progressive chronic kidney disease

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