Less-Obvious Predictors of Post-ICU Informal Caregiver Burden

To the Editor:

In a recent issue of CHEST (January 2010), Van Pelt and colleagues showed how predictors of caregiver burden vary over time. As their study emphasized the need to broaden the focus of patient- and caregiver-specific interventions, we have suggestions that can help to direct future research in this area.

The hospital admission of a seriously ill family member often imposes a substantial financial burden on the family, and this contributes to the overall burden on the caregiver. In a multicentric study comprising 2,123 admissions, the patients’ critical illness meant the loss of a major source of their family’s income for 29% of the caregivers. Hence, although the level of patient dependency on caregivers did not affect caregiver outcomes in the study by Van Pelt and colleagues, any data (either in this or future studies) on how many patients significantly contributed to the family income prior to admission and whether the number of patients returning to work varied over time can reveal how the change in the financial situation influences the caregiver burden.

The authors also suggested that caregiver burden may be affected by less-obvious factors like the caregiver’s perception of the patient’s suffering. We have earlier highlighted the concept of “inappropriate worry.” We correlated worry among caregivers 48 to 72 h after patient admission with their perception of change in the patients’ critical state and found a clear discrepancy. Out of 76 family members, only 50% experienced worry that was in keeping with the change in the patients’ condition. In the remaining 50%, the worry was incongruous. We also found that in more than one-half the cases, there was a discrepancy between the objective change in the patients’ acute status (measured as the change in the Acute Physiology and Chronic Health Evaluation II score since admission) and the caregivers’ perception of the change (subjective change) in the patients’ critical state. Although our study was cross-sectional, the long-term effects of this discrepancy, as well as whether mitigating this discrepancy relieves caregiver burden, remain to be explored. Finally, discerning whether satisfying relevant caregiver needs during a patient’s hospital course and follow-up has a long-term effect on the caregiver is another area that could help to identify targets to reduce caregiver burden.

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REFERENCES

Response

To the Editor:

We thank Dr Kulkarni for the thoughtful comments regarding our manuscript on post-ICU informal caregiver burden. Dr. Kulkarni identifies two interesting causes of burden that were not discussed in our article: loss of income and inappropriate worry.

Few studies have considered the financial impact of critical illness on informal caregivers. As the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment (SUPPORT) trial showed, the potential for loss of income by families of survivors of critical illness can be substantial. Although we did not investigate financial outcomes in our most recent article, we reported in an earlier study that up to 14% of caregivers stopped working in order to provide care for their loved ones.

Dr Kulkarni’s concept of inappropriate worry highlights the complexity of identifying correlates and causes of burden.